Please Be Patient

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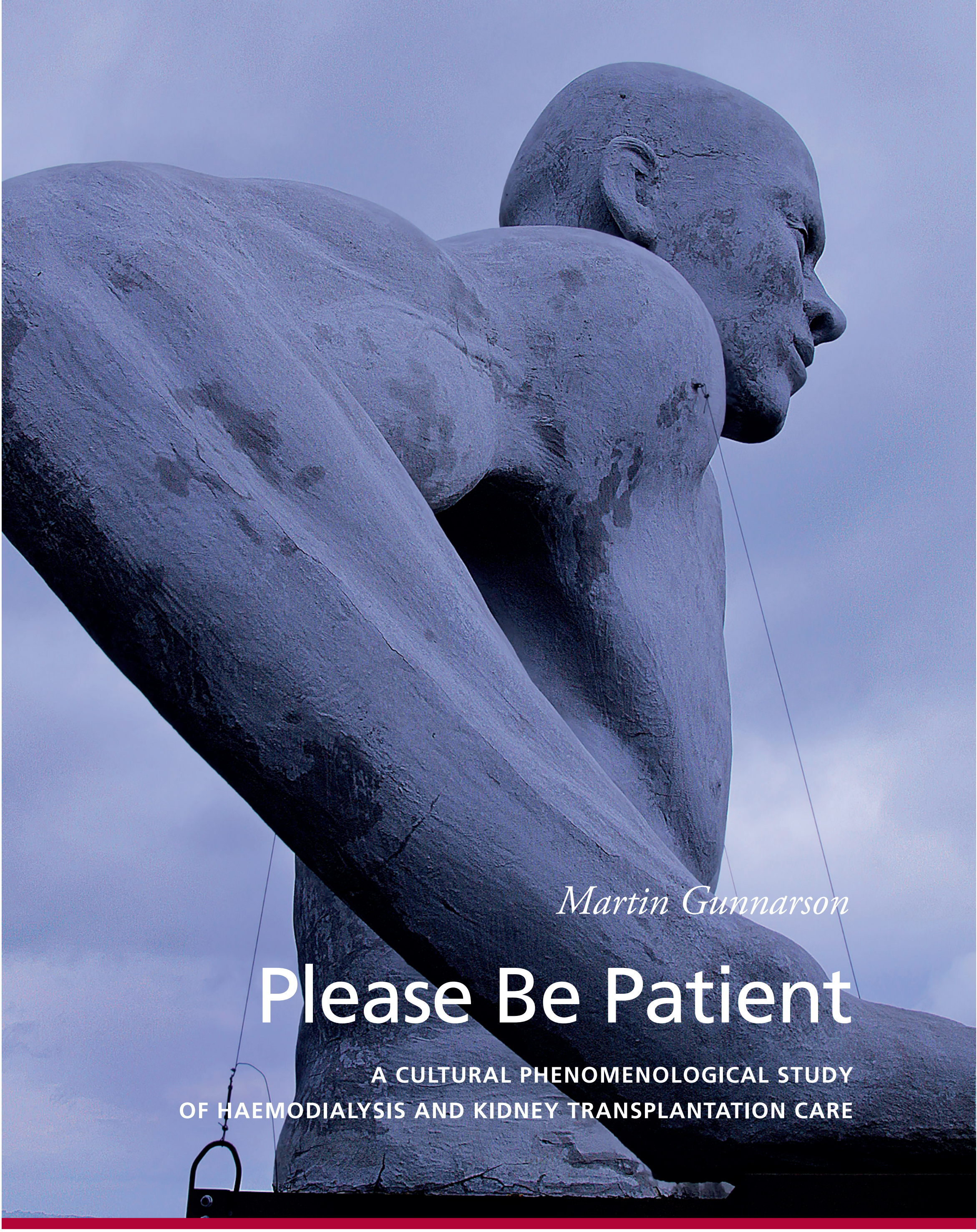

Martin Gunnarson

Please Be Patient

A CULTURAL PHENOMENOLOGICAL STUDY OF HAEMODIALYSIS AND KIDNEY TRANSPLANTATION CARE

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PLEASE BE PATIENT

Please Be Patient

A cultural phenomenological study of haemodialysis and kidney transplantation care

MARTIN GUNNARSON

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What has brought this book, this thesis, into being has not solely been the movement of my fingers over the keys of the computer I am now sitting at. Nor is it the result of a thought process that is entirely my own. Without the involvement in my work and life of the persons I am now about to thank, this thesis would never have seen the day of light. And neither would I, as the person, and researcher, that I am now. Perhaps this is why it is so difficult to find the right words as I am writing this. Throughout my endeavour to research and write this thesis, the persons I mention below have all contributed in various ways to the force that has pushed me forward towards finishing this thesis. So now, as I am turning to thank you all, this phrase, 'Thank you', suddenly feels utterly insufficient. But please know that although I only have words at my disposal, none of the words of which this thesis consists would have been possible without you.

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Martin Gunnarson
Bagarmossen, October 2015

1. Introduction

Carlos – I have already received a kidney once. Then you get antibodies against those genes. So now I need a kidney from a person with different kinds of genes. It doesn't work with any of my relatives.

Martin – So how does that work? Will you be admitted to a waiting list?

Carlos – Yes, now I'm going to be admitted to a waiting list, as of December.

Martin – How do you perceive that? How do you feel about that?

Carlos – Well, I don't think about it that much now. I was so obsessed with the fact that I was going to get a kidney from my sister and that everything would be as usual again, and when that didn't happen, I thought, 'Well, I have to change my attitude. Now only dialysis remains. So now I have to accept that and put up with that.'

Martin – And how does one do that? How does one manage to do that?

Carlos – [sighs] Well, human beings have the ability to adapt themselves. And then it's also the fact that Swedish health care is still very good. There are such things as self-care dialysis, which allows you to have as much dialysis as you want and need, and adapt it to your body. Because now I've had three times a week, and on those three occasions you're supposed to try to get your blood as clean as possible. The result is a very intense treatment, and that's not good for your body. So now when I'm at the self-care unit I can have five times a week and fewer hours, three hours instead of four. So I don't have to go around feeling bad after the treatment. It's gentler. And when I have the machine at home, then I can have six times a week and only do two and a half hours.

> Martin – Sure, that's different.
>
> Carlos – So it's… you have to adapt the treatment to your body. Four hours, and in those four hours you're supposed to reach as far as possible, that's hard on your body. So that's what I've learned. I can live with dialysis but I have to adapt it to me.
>
> Martin – Yes, and you feel that you have that opportunity…
>
> Carlos – Yes, because I can't adapt to dialysis, it can't be done. I know where my limits are. I know that it's hard to 'take off' a lot of fluid from me. I know that I feel bad after three hours. So I have to adapt dialysis to me. And that's what I'm doing now. To just [go around] thinking about transplantation, if a kidney turns up, well, thank God. But I can't go around thinking about that every day. I gain nothing from that.
>
> Martin – So the difference is that when you're waiting for a kidney from a deceased person you can't, as you put it, be obsessed with it in the same way, but rather you have to put it aside in a way, or…?
>
> Carlos – Yes, exactly, maybe you think that one day they'll call and say, 'Hello, there's a kidney for you here,' and then you go, 'Yes, please,' and it's just nice. But right now it's better to say to dialysis, 'Well, thank you for being there.' That's easier for me, or for the patient.

When I met Carlos in November 2010 he had recently returned to dialysis after living with a functioning transplant for thirteen years. Carlos underwent dialysis for the first time in 1997 when the autoimmune disease SLE[1] caused his kidneys to fail. But he did not undergo the treatment for very long since he was soon transplanted with a kidney donated to him by his mother. When, thirteen years later, the transplant began to lose its function, Carlos and his sister had already decided that she would give him one of her kidneys. But unfortunately, Carlos's body had developed antibodies, which made it impossible for him to receive his sister's kidney. At the time

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[1] The acronym SLE stands for systemic lupus erythematosus, which is an autoimmune disease that often affects the kidneys (Pattison et al. 2004, 53).

of our conversation, Carlos had just transferred to the self-care haemodialysis unit in Stockholm, where he was learning to perform the treatment by himself. Soon, he hoped, he would be admitted to the waiting list for a transplant from a deceased donor.

Dialysis and transplantation are the two treatment alternatives available for persons whose chronic kidney disease has entered the fifth and final stage, what in everyday care situations is referred to as kidney failure.[2] When this stage is reached, the glomerular filtration rate – the filtering capacity of the kidneys – is less than 15 mL/min. But it is not until this number falls below 4–5 mL/min – less than 10 per cent of normal kidney function – that renal replacement therapies – dialysis or transplantation – are required (Burden and Tomson 2007, 8). When the glomerular filtration rate is this low, the kidneys have almost entirely lost their capacity to produce urine and thereby rid the body of its toxic waste products. Without the immediate initiation of dialysis or the transplantation of a kidney, the outcome is fatal.

The vast majority of persons who fall ill with kidney failure encounter dialysis first. There are two types of dialysis treatment: haemodialysis and peritoneal dialysis. In haemodialysis the patient's blood is circulated through a machine that rids the blood of its toxins and removes excess fluid. This process ordinarily takes four hours and needs to be repeated three times a week. Typically, the treatment is carried out at a hospital unit. Increasing numbers of patients, however, are engaged in 'self-care haemodialysis', which means that they manage the treatment by themselves. Self-care is performed either at a medical facility or in the patient's home. The other form of dialysis treatment, peritoneal dialysis, is essentially a self-care treatment in itself. Three to five times a day the sick person infuses a dialysis solution into his or her abdomen, letting it remain for a while before draining it along with the excess fluid and toxic waste products it has attracted (Mcintyre and Burton 2007, 54–55). In this study, I focus solely on haemodialysis, which is by far the more common of the two types of

---

[2] Throughout this book I generally use the term kidney failure to denote the fifth and final stage of chronic kidney disease.

treatment.[3] This focus is motivated by my ambition to conduct a thorough investigation of the treatment practice, an ambition that would have been difficult to realise had I included two forms of dialysis in the study.

There are two ways in which a person suffering from kidney failure may receive a transplant: from a living or a deceased donor. In most countries in the world, living donors are related or in other ways emotionally attached to the recipient. However, in recent years, an increasing number of countries have begun to practice so-called 'unspecified donation' (Dor et al. 2011), where donors donate to an unspecified recipient who is unaware of the identity of the donor. If no suitable living donor is found, or if the potential recipient is unwilling to accept an organ from a living person, deceased donation is the alternative. But the waiting time for deceased donation is long in most countries, and while they are waiting, persons suffering from kidney failure must undergo dialysis.

Organ transplantation was the focus of the interdisciplinary research project *The Body as Gift, Resource and Commodity: Organ Transplantation in the Baltic Region*,[4] of which the present book is an outcome. It was within the frame of this project that I formulated the aims and objectives of my study. The project, which ran between 2008 and 2012, was financed by the Baltic Sea Foundation[5] and led by Fredrik Svenaeus, Södertörn University. Also involved in the project, besides Svenaeus and myself, were ethnologists Susanne Lundin and Markus Idvall, Lund University; and historian of ideas Ulla Ekström von Essen, Södertörn University. In addition, scholars of medicine Annika Tibell and C. G. Groth were tied to the project, functioning as advisors. The aim of the project was to explore the practice of organ transplantation through three metaphors: the body as a gift, a resource, and a commodity. Our presupposition was that these three metaphors were productive and reproductive of the meaning afforded to the transfer of organs within transplantation. We were particularly inter-

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[3] In Sweden, for instance, only around 841 of the 3,761 persons who underwent dialysis in 2010 were treated with peritoneal dialysis. See http://www.medscinet.net/snr/rapporterdocs/%C3%85rsrapport%202011.pdf, accessed 2015-09-30.

[4] https://www.sh.se/p3/ext/content.nsf/aget?openagent&key=projekt_page_eng_1304328654146, accessed 2015-07-07.

[5] http://ostersjostiftelsen.se/in-english, accessed 2015-07-07.

ested in the way the metaphors simultaneously affected and were affected by the relationship between person and body enacted in the practice of and discourses on organ transplantation. Our exploration of these themes was located in a particular geographical area, not only, as the title of the project indicates, in the Baltic region – meaning the countries around the Baltic Sea – but also in Eastern Europe.

While Svenaeus, from the point of view of phenomenology, investigated the ethics of organ transplantation (2010a), the nature of an organ (2010b), and the varying relations of different organs to personal identity (2012), Lundin (2012a; Berglund and Lundin 2012), by means of ethnographic fieldwork in Moldova, for instance, explored the commodification of the body taking place within the international and illegal trade in organs. Ekström von Essen and Idvall directed their attention towards the resource metaphor of the body. Ekström von Essen (2012) explored the view of organs as resources evident in ‘Swedish governmental and expert discourses on organ donation policy’, while Idvall (2012) studied the enactment of the body as a societal resource taking place within as well as between the transnational organ-exchange organisations Scandiatransplant and Balttransplant.[6]

When I set out to formulate the aims and objectives of my study, and began to read the relevant literature, I soon realised that the social scientific and humanistic research on organ transplantation had focused quite narrowly on the transplant event. The scholarly interest tended to be directed towards either the transformative force of organ transplantation – affecting the involved actors’ personal identities, their views of their bodies, and their relationships to others – or the sociocultural and political dimensions governing the transfer of organs from donors to recipients (see e.g. Fox and Swazey 1992; Sharp 1995; Hogle 1999; Lock 2002; Waldby 2002).

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[6] From 2012 to 2015 I was also involved in the research project *Combating trafficking in persons for the purpose of organ removal (The HOTT Project)*, financed by the Prevention of and Fight against Crime Programme, European Commission – Directorate General Home Affairs. The aim of this project was to increase knowledge about trafficking in human beings for the purpose of organ removal, to raise awareness about it among a number of target groups, and to improve the non-legislative response. See http://hottproject.com/, accessed 2015-07-07.

Studies that thematised organ recipients' experiences of living with a transplant in the long term were few (see e.g. Crowley-Matoka 2005; Sharp 2006; Amelang et al. 2011). Even fewer were the studies that included an analysis of the recipients' first encounter with organ failure and what they experienced on their way towards transplantation, not to mention their experiences of organ rejection and retransplantation (see e.g. Kierans 2005; Russ, Shim, and Kaufman 2005; Åhdal 2012).

In light of these gaps in the literature, my interest became directed early on towards the events that take place before and after the actual insertion of an organ into a person's body. My hypothesis was that some of these events are likely to be deeply transformative, thereby influencing how a person experiences receiving a transplant. Here I found kidney transplantation particularly interesting, not least since for kidney failure, unlike other forms of organ failure, two forms of treatment exist: transplantation and dialysis. As I have already mentioned, persons who fall ill with kidney failure often undergo dialysis before they receive, and while they wait for, a transplant. Dialysis is also the treatment to which they return if and when their transplant ceases to function. Considering this pervasive presence of dialysis, and particularly haemodialysis, in the lives of kidney failure patients, and the absence of any thorough analyses of it in the literature, I decided to make it one of the main focuses of my study, along with the disease and the other treatment alternative, transplantation.

The relevance of taking the study in this direction becomes even more evident when one takes account of the fact that the majority of dialysis patients are not even eligible for transplantation. Most are either too ill or too old to be deemed suitable candidates for the procedure. Of the 3,857 persons who were undergoing dialysis in Sweden by the end of 2013, for example, only 626 (approximately 16 per cent) were admitted to the waiting list for transplantation.[7] Admittedly, some of the remaining 3,231 persons were likely waiting to be admitted to the waiting list for the first, second, or perhaps even the third or fourth time. Others had already un-

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[7] For statistics on the provision of renal replacement therapy in Sweden see http://www.medscinet.net/snr/rapporter.aspx, accessed 2015-06-12. For statistics concerning the waiting list for transplantation see http://www.scandiatransplant.org/data/scandiatransplant-figures, accessed 2015-06-12.

dergone one or more transplantations and had now been deemed ineligible for another. For the majority, however, transplantation would never become an option. They would have to settle for dialysis for the rest of their lives.[8]

That dialysis is an inferior treatment compared to transplantation is generally stated as a self-evident fact in the medical and bioethical literature (see e.g. Monaco 2007; Abouna 2008; Cronin 2008; Matas and Chapman 2008). Radcliffe-Richards et al., for example, describe dialysis as a 'wretched experience' (1998, 1950), while, according to Omar, Tufveson, and Welin, 'receiving a healthy kidney is a second chance at a normal life, a possibility to get back into society' (2010, 94). In this literature, organ transplantation is often portrayed as a simultaneously miraculous and standard therapy, as a straightforward yet spectacular medical achievement. Although seemingly contradictory, this portrayal does not constitute a paradox since the capacity of medicine to transform the miraculous lifesaving power of transplantation into a standard procedure is itself often seen as part of the miracle (see e.g. Ambagtsheer, Zaitch, and Weimar 2013, 3).

In directing its focus primarily towards the transplant event, the social scientific and humanistic research on transplantation has, to some extent, participated in the portrayal of the procedure as a spectacular medical invention, as that which instigates the most radical transformation of the selves of those who undergo it and therefore warrants a thorough investigation. This focus has not been unjustified. As the research itself has illustrated, organ transplantation is an exemplary object of study if one wants to explore the transformative effects of new medical technologies. But, as has unfortunately been the case, this fascination with transplantation has oriented scientific inquiry away from the more mundane and less spectacular medical therapies, such as dialysis. In a similar vein as Hoeyer (2010) and Koenig (1988), therefore, I want to highlight and explore the often transformative and dramatic nature of treatments that are seen as mundane and, as in the case of haemodialysis, substandard. But I also wish to gain

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[8] When faced with the option either to undergo dialysis for the rest of their life or to die, some choose the latter. It would be interesting to study the motives underlying such a choice, but that is beyond the scope of this study. Here, my focus is solely on persons who choose to undergo renal replacement therapy.

insight into the very process of routinisation that commences when patients begin to undergo highly technological medical therapies such as haemodialysis. My intention in including both transplantation and haemodialysis in my analysis is to explore how persons with varying experiences of the two treatment alternatives perceive the relationship between them.

In contrast to previous studies concerned with organ transplantation in general and kidney transplantation in particular, I study the procedure from the perspective of dialysis, or more specifically from the perspective of haemodialysis. By means of ethnographic observations at four haemodialysis units – one in Riga, Latvia, and three in Stockholm, Sweden – and in-depth interviews with patients at these four units, I approach transplantation from the perspectives of persons who are undergoing haemodialysis and who have varying experiences of the two treatment alternatives. Among the participants in this study there are those who have recently encountered haemodialysis and those who have been having it for more than twenty years. Some of them have yet to be placed on the waiting list for transplantation and others will never be on the list. Some have undergone all the tests required and are actively awaiting their first transplant, while others are undecided as to whether or not they should initiate the admittance procedure for a third or fourth one.

What they all have in common, however, is that, at the time of the interview, they are undergoing a medical treatment that penetrates deeply into their lives. The vast majority of them spend twelve hours weekly, divided into three treatment sessions, connected to the haemodialysis machine. They go to a hospital unit, assume the role of a patient, and let their blood flow through a machine that rids it of excess fluid and toxic waste products. Persons who rely on haemodialysis for their survival thus spend a large portion of their daily lives as patients, to the extent that patienthood becomes a significant feature of their personhood. Patienthood and personhood, therefore, constitute two basic categories by means of which I analyse my empirical material in the present study.

Aims and research questions

The aim of this thesis is twofold. On the one hand, the aim is to examine the forms of person- and patienthood enacted and negotiated in haemodialysis and kidney transplantation care and in the daily lives of persons with kidney failure. On the other hand, the aim is to investigate the ways in which the enacted and negotiated forms of person- and patienthood are culturally embedded and normatively charged.

In order to fulfil this aim, I have formulated a number of research questions, which I endeavour to answer in the following chapters. The first of these questions concern the initial encounter of persons with kidney failure with the illness, the diagnosis, and the two treatment alternatives. My questions are: How do kidney failure, haemodialysis, and kidney transplantation, in both theory and practice, enter into the lives of those who fall ill, and in what ways do these experiences force them to transform and reorient their personhood and direct themselves towards patienthood? How do persons who fall ill with kidney failure come to terms with and come to understand their new situation?

My next couple of questions concern the haemodialysis practice, and I direct my attention towards the forms of patienthood enacted here. Since persons with kidney failure spend several hours a week as patients at a haemodialysis unit, the nature of this patienthood has a profound impact on their life and self-understanding. The questions are: How is patienthood spatially, temporally, and bodily enacted in the practice of haemodialysis? What forms of patienthood are the result and how do patients experience, enact, and negotiate them?

As my interest extends beyond the sheer practice of haemodialysis to the life that persons undergoing haemodialysis live when they are not at the treatment unit, I also ask: How do haemodialysis patienthood and kidney failure spatially, temporally, and bodily enter into and orient the life of persons with kidney failure? What forms of personhood are the result and how do the sick persons experience, enact, and negotiate them?

Being the only alternative to haemodialysis for persons with kidney failure, transplantation is always more or less present in their lives. Some have already been transplanted on one or more occasions, others are waiting for their first transplant, while still others have been deemed ineligible for it. Here I pose the following questions: How is the alternative of transplantation perceived and acted upon from the perspective of haemodialysis patienthood? In what ways do previous experiences of transplantation affect how persons undergoing haemodialysis are oriented towards the transplant alternative?

A basic presupposition of this study is that the practice of contemporary biomedicine is deeply embedded in and shaped by the cultural, historical, economic, and political circumstances provided by the particular local, national, and supranational contexts in which it is practiced (see e.g. Kleinman 1988; Martin 1994; Lock and Nguyen 2010). But it is not only the practice of biomedicine that is situated in this sense. So too is the very science on which it is based. Scientific endeavours, research has shown, are oriented by morally and normatively charged notions of what problems should be solved, notions that rely on technological materialities and practices that direct the perception and intentions of the scientists (see e.g. Ihde 1993; Reiser 2009; Lock and Nguyen 2010; Sharp 2014). As Lock and Nguyen have asserted, 'Biomedicine itself is a technology' (2010, 11), by which they mean that it is not only contextually embedded, but also, in and of itself, productive and reproductive of pervasive norms, values, desires, and intentions. Due to the cultural embedment of biomedicine, these are norms, values, desires, and intentions that often, though not always, mirror those predominant in other spheres of society (see Jönsson 1998, 20–21).

Thus, when a person becomes oriented as a patient within the practice of biomedicine, this person orients him- or herself along the lines of a normatively charged practice that is by no means sealed off from the cultural context in which it takes place. The personhood and patienthood studied here are therefore not only deeply intertwined with each other but also inherently non-neutral and culturally moulded. This cultural embedment is multileveled; it is local, national, and transnational, and it is an ambition of this study to examine how the embedment of renal replacement therapies in various local, national, and transnational contexts affects what forms of person- and patienthood become enacted and negotiated (see Lock and Nguyen 2010; Beck 2012). How do particular clinical realities influence what forms of person- and patienthood take shape? How do national contexts figure in? To what extent and in what ways do the particular biomedical therapies studied constitute transnational practices transcending the borders of nation states, creating a form transnational patienthood? A presupposition of this study is that these three levels tend to be deeply intertwined, to the extent that they shape each other. But they rarely totally merge. In some situations and regarding some aspects of the practices studied, one level may take precedence over the others.

In order to explore this multileveled nature of cultural processes in general and biomedical practices in particular, I have located the study in two national settings. Since, as I have already mentioned, the geographical scope of the interdisciplinary research project of which the present book is an outcome was the Baltic Sea region, I chose to locate my study in Sweden and Latvia, or more specifically, in Stockholm and Riga, the capitals of the two countries. But I do not presuppose these two national contexts to be relevant units of analysis concerning all situations and every aspect of the biomedical practices and daily lives studied (cf. Beck 2012). Rather, I take my point of departure in the enactment of person- and patienthood taking place in these practices and these daily lives, and attempt to discern, from situation to situation and aspect to aspect, how cultural processes on the various levels mentioned above interact, relate to each other, and shape the involved actors' actions and experiences.

Materials and methods

In order to conduct such an investigation, I have gathered a body of empirical material consisting of ethnographic observations performed at four haemodialysis units, one in Riga and three in Stockholm, and of in-depth interviews with patients and medical practitioners who, at the time of the study, were either receiving their care from or working at any of these units. In addition, I have conducted interviews with transplantation surgeons, social workers, representatives of patients' associations, a lawyer, and a kidney failure coordinator. Forming a background to these two main categories of empirical material are information brochures and pamphlets gathered at the four haemodialysis units and statistics, guidelines, and various policy documents primarily derived from the Internet. In what follows I give an account of how I gained access to the field, how I gathered and processed the empirical material, and the measures I took to ensure the ethical viability of the study.

Meeting the field

I started my fieldwork at the unit in Riga in the fall of 2009. In May that year I had accompanied ethnologist Markus Idvall, a member of the interdisciplinary research project of which the present study is a part, when he went to Riga to conduct interviews with transplantation surgeons and coordinators. In the course of our weeklong stay, I was able to get oral consent from a nephrologist to conduct the study at the unit where she worked. But I still needed to apply for an ethical permission from the hospital's board of ethics, which I did. And in the early fall of 2009 I was granted permission to conduct my study at the unit.

But one obstacle remained. Since I speak neither Latvian nor Russian – a significant part of the Latvian population is Russian speaking – I needed the assistance of an interpreter. Fortunately, Aivita Putnina, an anthropologist at the University of Latvia, proved able to help me. She recruited three of her students, who assisted me with interpretations during the course of my fieldwork.

In the spring of 2010 I began preparing for my fieldwork in Stockholm. Ethnologist Sara Berglund, who was a member of the interdisciplinary research project for a time, and I met with medical practitioners in the fields of nephrology and transplantology in hopes of getting insight into the organisation of care practices and the preparations necessary to gain access to this field. What I learned first of all from these meetings was that the way the provision of haemodialysis was organised in Stockholm differed from the way it was organised in Riga on one important point. In Riga, the patients' affiliation to a particular haemodialysis unit was based primarily on their place of residence, whereas in Stockholm it was first of all the severity of the patients' medical condition that determined which unit they received their care at. I realised that in order to meet persons with a wide range of experiences of haemodialysis and transplantation, I would need to conduct fieldwork at three units in Stockholm. Before contacting the head nurse of each unit, which I was advised to do, Sara Berglund and I began the process of applying for ethical permission – we submitted a joint application for our respective projects – and in April 2010 it was approved. The approval was conditioned, however: I was required to obtain informed consent from all patients present during my observations at the units. This caused me some concern, since if only one person declined to participate in my study, the whole enterprise would be compromised. To my relief, the head nurses at all three units helped me limit my observations to certain rooms or parts of the units so that I only had to obtain informed consent from a few persons. Consequently, only patients who gave their explicit consent to take part in the observations figure in my accounts of the events I observed. This is not the case when it comes to the unit in Riga, where the ethical permission allowed me to include all patients in my observations without obtaining informed consent from them individually. Before each observation, however, I made sure that Dr Liepa, my contact person at the unit, had informed the patients and the personnel about my presence.

My access to the field was thus conditioned in different ways in Stockholm and Riga, but both ethical approvals specified that I had to obtain informed consent from all persons I wanted to interview, medical personnel as well as patients. I presented each potential interviewee with a letter in which I briefly described my study and the nature of the interview as well as the interviewee's right to discontinue his or her participation at any time. The same procedure preceded my observations at the units in Stockholm, except that the letter was directed only to patients and briefly detailed the nature of my observations rather than my interviews. Both letters contained an informed consent form. When filled out and signed by a person, this form allowed me to interview and observe him or her.[9]

Due to the different ways in which my access to the field was conditioned, and to my lack of knowledge of Latvian and Russian, the recruitment of participants for the study differed between Stockholm and Riga. In both contexts, however, the medical practitioners functioned as a form

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[9] See appendix 1.

of '*gatekeepers*' (Idvall 2005, 14, emphasis in the original). At the units in Stockholm, the head nurses decided in which rooms and with which patients I would conduct my observations. In this way, they also influenced which persons I interviewed, since I often ended up interviewing persons I had already observed. In Riga I was even more dependent, if possible, on the medical practitioners as gatekeepers. Since I speak neither of the languages spoken, I could not get to know anyone before I interviewed them. I was entirely reliant on Dr Liepa's view of who was appropriate to interview, taking into account their health condition and my wishes. In Stockholm, I could get to know the patients and the medical personnel through my observations and therefore more freely decide who I would ask about their willingness to participate in an interview. Here I was also able to talk about my study in my own words, whereas in Riga I was totally dependent on Dr Liepa's interpretation of the description I had given her.

As I have already mentioned, I began my fieldwork in Riga in the fall of 2009 and returned for a second and third visit in the winter and spring of 2010. In all, I spent a little over two months in the city, staying in an apartment I rented cheaply from a man I got to know in the Swedish-Latvian Society. I then devoted the fall of 2010 and spring of 2011 to fieldwork in Stockholm, where I live and work.

Conducting observations

My ambition when I conducted observations at the four haemodialysis units was to gain knowledge about the nature of the treatment practice that had so forcefully made its way into the lives of the persons with kidney failure. I wanted to explore the characteristics of the particular forms of patienthood that were enacted there and to try to discern its cultural embedment and normative charge.

But how does one go about conducting observations in a setting where one neither speaks nor understands the languages spoken? When I set out to conduct observations at the unit in Riga I had no answer to this question, but I was convinced that observing the events that took place during a haemodialysis session would provide me with at least a superficial knowledge of the treatment practice. Accompanying this conviction, however, was the nagging concern that I would misinterpret everything I saw.

Despite this, I gave it a try, and during my three fieldwork periods in Riga I experimented with several ways of observing, the first of which would turn out to be the most successful. During my first period of fieldwork in Riga I tested a mode of observing in which I was rather detached from the treatment practice and the persons involved in it. During the course of an observation I remained in the glass cubicle from which the nurses and nephrologist on duty monitored the state of the patients and the progress of the treatment. This detachment was both positive and negative. On the one hand, it enabled me to assume a position of exteriority which allowed me to 'crawl up' into a corner of the haemodialysis ward and, without affecting and disturbing the practice too much, take detailed notes of the events I saw and the sounds I heard. On the other hand, not being able to understand and fully participate in the events that took place made the nagging feeling of misinterpretation even more intense. Perhaps my inability to reach the depths of the practice made the knowledge that I gained unreliable (cf. Bäckman 2009, 131). Nevertheless, when I performed my first interviews I noticed that what I had seen and heard during the observations – the conversations between patients, the orientation of the nurses towards the haemodialysis machines, the presence of crossword puzzles, books, and computers, the location of the machines in relation to the patients, and so on – constituted valuable knowledge. By means of this knowledge I was able to pose questions about the immediate practice of the treatment, questions which, in turn, made it possible to verify or modify my (mis)interpretations of the events I had observed.

Despite these partly positive results I was still eager to make an attempt at bridging the detachment and superficiality that observing from the perspective of the glass cubicle had created. I hoped to accomplish this by accompanying a nurse or patient during a treatment session. I wanted to reach the depth of the practice by 'seeing together' with another person's eyes, as ethnologist Maria Bäckman puts it (2009, 130). What made this difficult, however, was that none of the nurses spoke English, and whether or not there were any English-speaking patients was at the moment unknown to me. Despite this language barrier, I still wanted to try if a more participatory or 'go-along' mode of observation was possible (Kusenbach 2003). During my second period of fieldwork in Riga, I made two such attempts, both unfortunately more or less unsuccessful.

The unsuccessfulness of the first attempt was, I believe, due to the language barrier. The problem was that Marija, the nurse I accompanied, did not encourage me to join her when she went out into the haemodialysis ward to fiddle with a machine or talk to a patient. Instead I remained in the glass cubicle and watched Marija's work from a distance. I believe that this had to do mainly with my dependency on Dr Liepa to convey my intentions to Marija. Somewhere along the way, the details of my method of observation had been lost. If I had known Latvian, it would have been possible, together with Marija, to work out a way of performing the observation that better took into account both the conditions of her work and the specificities of my method.

The unsuccessfulness of my second attempt at participant observation was, I would argue, due to the nature of the treatment itself. During this observation I accompanied the English-speaking patient Egils, who had agreed to let me sit beside his bed as he underwent the treatment. And now, one Monday morning, there I sit. The first half-hour of the treatment, when Egils and his fellow patients are being connected to the dialysis machines, is rather eventful. Nurses run back and forth between the ward and the glass cubicle, and there are several conversations going on. But once all the treatments have been started, things calm down. Patients begin to read, watch TV, sleep, or talk quietly with the patient next to them, while the nurses move back into the glass cubicle or run off to do some errands. There is not much going on in general, and even less in the area around Egils and me. I ask him some questions and we engage in small talk, but I do not want to initiate a proper interview during the treatment. I know that Egils has brought magazines to read and that he usually takes a nap while he undergoes the treatment. Sitting there, I now begin to feel that I am intruding on him. I feel I am preventing him from doing what he usually does during the treatment. I am unsure if I should talk or just sit there quietly watching, but in what direction should I direct my gaze? Not much later, the feeling of intruding becomes unbearable, so I excuse myself and tell Egils that I will be back later for his disconnection from the machine. In the meantime I go home to my apartment and contemplate what has just transpired.

I believe the mistake I make when I sit beside Egils during the treatment is to limit the little influence he has over the content of the time he spends connected to the machine. During the treatment, Egils's agency is greatly circumscribed. He cannot move, and his influence over the events that take place is almost non-existent. When I am sitting beside him, therefore, I prevent him from enacting the strategies he has developed for managing this vulnerable position – reading and having a nap – and I single him out as the agent of my observation – as the person who is supposed to teach me something – even though his agency is radically restricted.

In summation, my fieldwork in Riga consisted of three 'successful' occasions of observations, each stretching over the course of a haemodialysis session. These observations were conducted either from inside the glass cubicle or from the chairs placed just outside it and were hence of the more detached and superficial nature that I have described above. However, the occasions of observation that I have labelled 'unsuccessful' also contributed to my empirical material, not only as warning examples but also as situations where I took notes from the point of view in which I ended up. During my three periods of fieldwork in Riga, I visited the haemodialysis unit almost every day. The purpose of these visits was ordinarily either to conduct interviews or observations or to meet people in order to inquire about their willingness to participate in the study at a later date, so I spent a lot of time in waiting rooms and running around corridors looking for people. Experiences like these also found their way into my field notes and make up an important background to the more structured observations.

When I was preparing for my fieldwork in Stockholm the knowledge I had gained in Riga was invaluable. I was convinced that, since I knew the language spoken, it would be possible to conduct more participant, less detached, observations. Yet, with the experience of sitting next to Egils during the treatment fresh in my memory, I decided to try to observe the haemodialysis practice primarily through the eyes of the nurses.

As I mentioned above, in Stockholm the medical conditions of the patients differed between the three units where I conducted fieldwork. One unit, which I will henceforth call 'Unit 1', treated the most critically and recently ill. For this reason, there was a fairly large degree of flexibility built into the practice. A structure had been established that allowed for immediate changes if, for instance, a patient's condition suddenly got radically worse. At the unit I call 'Unit 2' the regularity of the treatment was more apparent; the vast majority of patients always received their treatment at the same machine. Here, severely ill but stable patients underwent haemodialysis. Conducting self-care at the third unit, 'the self-care unit', were patients with less critical conditions. Many of the persons who came here studied or worked part time. As a consequence, this practice was also endowed with a fair amount of flexibility. But at this unit, unlike Unit 1, the character of the flexibility was primarily shaped by the patients' commitments outside the unit.

At Unit 1 and Unit 2 the vast majority of patients relied on the nurses to start, monitor, and terminate their treatment. When I conducted observations there, I therefore accompanied the nurses. At the self-care unit, the nurses were much less involved. The vast majority of the patients managed the entire treatment procedure by themselves. So if I were to gain insight into haemodialysis as it was practiced there I would have to accompany the patients, which was what I did. At all three units in Stockholm I was thus able to bridge – though obviously not completely eradicate – the detachment that characterised my observations in Riga. By physically accompanying, and by listening to and asking questions of nurses and patients, I was able to reach further into the 'multi-layered depth' of the haemodialysis practice (Bäckman 2009, 131). As a consequence, my presence was also more apparent. Not only were things explained to me, but my very presence evoked the telling of certain stories. The nurses and the patients also often asked me questions about my research, and this, in turn, frequently spawned long exchanges about the character of life with kidney failure and renal replacement therapies. Thus, my embodied presence 'as an active, situated, participant in the construction of accounts and representations' was much more apparent during my observations in Stockholm than during those in Riga (Turner 2000, 51).

But the observations I conducted in Stockholm were not homogeneous. Whether I saw and heard the practice through the eyes and ears of a nurse or a patient made a great difference. Before I started my fieldwork at the self-care unit, I was worried that accompanying patients would again prove problematic. But to my surprise, I found that I often almost unwittingly stayed with a patient whose eventful starting procedure I had just observed. Why I did not experience this as an intrusion on the patient's privacy was, I realised, mainly due to the conversations that the patient and I were often already engaged in. These conversations, I believe, were the result of the relative absence of nurses, with the patients taking on the role of active demonstrator. Since they managed the treatment by themselves, the self-care patients often explained to me what they were doing, accounts that paved the way for further exchanges. At Unit 1 and Unit 2 such conversations were fewer. Here, unsurprisingly, I interacted more with nurses than with patients. When I joined the nurses as they approached a patient, I became more of an observer, standing at the foot or side of the bed. On some occasions this meant that my presence did not influence events very much – the nurses and patients seemed to go about their business as they normally would – while on other occasions I was more involved in the interaction, participating in the conversations that took place.

The character of my observations and interaction with patients and nurses were not determined only by the person I accompanied; it also relied on the spatiality of the unit. At Unit 2 and the self-care unit the treatment took place in small rooms with a maximum of four patients in each. This limited space not only encouraged patients to talk with each other more but also allowed me to be present in the room without singling out one patient on whose privacy I intruded. At these two units, therefore, I was more available to the patients, and this promoted their taking the initiative to start conversations with me on several occasions. In the open space of Unit 1 there was nowhere I could place myself that was not too far away from the patients, but when I felt that it would not be an imposition on a patient's privacy – if, for instance, he or she was awake but not doing anything special – I would carefully approach him or her and initiate a conversation.

To all my observations, in Riga as well as Stockholm, I brought a small notebook. Different settings and situations called for different ways of using of it. In Riga, as a result of my relative detachment from the practice, I had the notebook in my lap almost all the time, taking notes on what I saw and heard. In Stockholm, as my style of observation was more participant, the notebook spent more time in my pocket, though I took it out now and then to write down a quote or the main points of an event. Typically, after observing the start or end procedure of a treatment session or participating in a conversation, I ran off to a desk or a lunchroom to summarise what I had seen or heard. When I returned home after a day of observations I made a fair copy of my notes on my computer.

In Riga I spent the better part of three four-hour haemodialysis sessions observing the treatment practice. In Stockholm my visits were longer. I typically arrived at seven in the morning and left between one and two in the afternoon, and repeated this procedure three or four times per unit. But it was not merely the length of the observations and the methods used that differed between the two national contexts. My ability to understand what was said and to participate to a greater extent in the practice in Stockholm made an enormous difference in the quality of the observational material I gathered.

Conducting interviews

My aim when I interviewed persons undergoing haemodialysis was to gain an in-depth understanding of the interviewees' experiences of and views on being a patient in renal replacement care and being a person in need of these forms of treatment. I was equally interested in what it was like to take part in renal replacement therapies as a patient and what it was like to live a life with kidney failure, depending on such therapies for one's survival. What especially caught my interest was the interplay between these two aspects of life with kidney failure. When I interviewed medical practitioners my aims were different. In these interviews I wanted to gain an extended understanding of the interviewees' work tasks as well as their experiences of and views on their role in the care practice and their interaction with patients. My interest here, in contrast to the interviews with patients, was not to such a great extent directed towards their personal lives.

If, as we saw above, there is a tilt towards the units in Stockholm when it comes to the observations, there is a corresponding tilt towards the unit in Riga when it comes to the interviews. Of the forty-two persons I interviewed during my fieldwork, twenty-seven were from Riga. In Stockholm

I interviewed ten patients, three haemodialysis nurses, one nephrologist, and one kidney failure coordinator. Of the patients, six were men and four were women, with ages ranging from thirty to seventy-three years old. In Riga I interviewed fifteen patients,[10] two representatives of patients' associations, three transplantation surgeons, two haemodialysis nurses, two nephrologists, two social workers, and one lawyer. Of the fifteen patients, nine were men and six were women, with ages ranging from twenty-two to sixty-nine years old. All of the interviewed nurses and two of three of the nephrologists were women, and all of the transplantation surgeons were men. In both countries, my aim when recruiting patients for interviews was to meet persons with a wide variety of experiences of and perspectives on haemodialysis and transplantation.

Why did I conduct more interviews in Riga than in Stockholm? There are two reasons for this. The first has to do with the detachment and lack of depth that characterised my observations at the unit in Riga. Since I do not speak the languages spoken it was only through the interpreter-assisted interviews that I could gain a comprehensive understanding of renal replacement therapies as they were practiced there. Second, much of the background information that I needed, in the form, for instance, of statistics and policies, was published only in Latvian. In order to obtain such information, I had to meet the people who possessed it. This is why I conducted interviews with social workers, representatives of patients' associations, a lawyer, and so on.

A majority of the interviews performed in Riga were carried out at the hospital where I conducted my study. On my first day of fieldwork, my contact person, Dr Liepa, provided me with an extra key to her consulting room, where twenty-four interviews were subsequently carried out. Before or after the treatment, patients came down to the consulting room to participate in the interview. Initially, I was worried that doing interviews in such close conjunction with the treatment would affect the patients' health, but this did not seem to be the case; a majority appeared to enjoy the conversation. An additional worry that preoccupied me was the risk

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[10] For an overview of all interviewed patients and some brief information about them, see Appendix 2.

that the medical setting would prevent the patients from expressing themselves freely. But this concern, too, would prove uncalled for. My impression was that the patients felt free to take a vast array of positions in relation to their care and their caregivers. The interviews that were not carried out in Dr Liepa's consulting room took place in the office of the person I interviewed. One exception was the interview with the president of the Latvian Association of Kidney Patients, which took place while she underwent haemodialysis at a private clinic.

In Stockholm the locations for the interviews were more varied. This was largely due to the fact that I could communicate directly with the persons I wished to interview and thereby be more attentive to their wishes. A common desire among the patients was to be interviewed during the treatment. In general, as we shall see in the chapters that follow, haemodialysis patients value their time away from the treatment a great deal. But they also struggle to endow the time they spend connected to the machine with meaning. Thus, many saw the interview as a way of simultaneously passing the time connected to the machine and keeping their free time intact. My ambition was to meet these desires as much as possible. I was concerned, however, that the spatial openness of the units risked compromising the privacy I wanted for the interviews, but on all occasions, the nurses helped me prevent this from happening. They either moved the treatment into a single room or screened the treatment place off by means of movable screens. In the end, five interviews were conducted in this manner. Four of the remaining five interviews with patients were carried out in their homes, while one was performed at the unit, after a treatment session. The interviews with medical professionals were carried out either in their offices or in conference rooms belonging to the units.

The interviews were semi-structured, which meant that they all, to some extent, followed the themes of an interview guide. I made different interview guides for different categories of interviewees: one for patients, one for nurses, one for nephrologists, one for transplantation surgeons, and so on. The guide I used when interviewing patients contained themes such as 'falling ill', 'living with haemodialysis', 'relation to staff and fellow patients', 'transplantation', and 'the waiting list'. In both Stockholm and Riga, however, I tried to allow the chronology of the interviewees' stories to shine through. My ambition was to pose my questions in such a way that they linked on to the themes just described by the interviewee, while simultaneously covering the themes of the interview guide.

The interviews I conducted in Riga and Stockholm differed in many ways.[11] Unsurprisingly, this was due to the fact that I relied on the assistance of an interpreter in Riga. This reliance made the interviews more formal and less emotional than the ones conducted in Stockholm (cf. Murray and Wynne 2001, 165; Borchgrevink 2003, 113;). Further, the scarcity of detail in the interpreters' simultaneous interpretations made it difficult to pose relevant follow-up questions, thereby allowing the interviewee's own story to guide the conversation. This increased my reliance on the chronology and structure of the interview guide. The distance that was thus created between the interviewee and me made it difficult to achieve the level of confidence required for going into great emotional depths. In Stockholm, on the other hand, my fluency in the language allowed me to be more open to the directions taken by the interviewee's story and to pose more emotionally sensitive questions.

All interviews were recorded digitally and transcribed verbatim. The interviews conducted in Riga were transcribed and translated into English by the interpreters, while I transcribed and translated those carried out in Stockholm. An interview was, on average, one and a half to two hours long.

Conducting interpreter-assisted interviews

Since I neither speak Latvian nor Russian – eight of the seventeen patients I interviewed were Russian-speaking – I depended on the assistance of an interpreter during the majority of the interviews in Riga. During the course of my fieldwork there, three interpreters – Katrina K., Katrina G., and Ilze – assisted me, all of whom studied anthropology at the University of Latvia. During the first two of the three fieldwork periods, I worked with one interpreter, Katrina K., who was fluent in both Russian and Latvian. From the outset, my intention was that we would collaborate

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[11] I elaborate on this further in the next section.

throughout my three stays in Riga, not least since we had developed a well-functioning method of working together. But in the end Katrina K. had too much to do with finishing her own master's thesis and participating in various research projects to be able to continue her work with me. Between my second and third fieldwork periods in Riga Aivita Putnina helped me recruit two new interpreters: Katrina G. assisted me during interviews with Russian-speaking persons and Ilze during interviews with those who spoke Latvian.

The interpreters' knowledge of anthropology was a significant asset for the method of interpretation I wanted to use. Inspired by the work of anthropologist Axel Borchgrevink (2003) and psychologists Craig D. Murray and Joanne Wynne (2001), my aim was to involve the interpreters as much as possible in the study. This meant that before beginning the actual interviewing, I not only provided them with the interview guide but also met with them and thoroughly discussed the themes and objectives of the study (cf. Murray and Wynne 2001, 162; Borchgrevink 2003, 112). My intention was to enable the interpreters to take on a fairly active role during the interviews. In practice this involved conveying to them the purpose of the questions, so that they would be able to ask follow-up questions from the perspective of my general inquiries. This way, the interpreter did not constantly have to take a detour via me in the event that the question I had asked had not received an exhaustive answer.

In addition, I encouraged the interpreters to let the interviewees give extensive descriptions if such were needed, and only in extreme cases to interrupt the account to facilitate an interpretation. This method, too, required fairly deep insights into the themes and objectives of the study, since the interpreter had to be capable of summarising the extensive description into a condensed account containing the essential information required for me to pose a follow-up question or move on to another one. Thus, I neither – as Murray and Wynne propose as two possible approaches – left the interviewing entirely to the interpreter nor used her as a mere translation instrument (2001, 164). Instead, I tried to simultaneously be the director of the interview and be open to the direction given to the interview by the interpreters' follow-up questions. This way of conducting interpreter-assisted interviews demanded a lot of the interpreters. But I felt that the fact that all of them had experience of and were interested in ethnographic fieldwork inspired them to take on this challenge (Murray and Wynne 2001, 161).

However, there were more methodological issues that required consideration. I perceived the two main problems to be, first, the distance between researcher and interviewee created by the need to go through an interpreter, and, second, the disappearance of details occurring when the interpreter was forced to summarise the interviewee's account.

According to Borchgrevink, the distance between interviewer and interviewee, which characterises interviews assisted by an interpreter, may not be problematic if, as I have described above, one involves the interpreter in the study. Nevertheless, since I was the one who determined the direction of the conversation, it was of great importance that I be able to instil trust between the parties involved. During the course of my fieldwork in Riga, I endeavoured to achieve such confidence, again inspired by Borchgrevink (2003, 110), by arranging the seating so that I was always facing the interviewee, and by trying to use all of the little knowledge I had gained of Latvian and Russian.

The problem of the disappearance of vital details in the simultaneous interpretations carried out during the interviews dawned on me only after I received the first few finished translations. When all of the interviewees' words were visible to me, I realised that there were some follow-up questions that had not been asked. This was an effect of the necessity in simultaneous interpretation to summarise and leave out parts of the interviewees' accounts. The translations carried out during the interviews had occasionally lacked essential information which, had I known about it, would have provoked me to linger on the subject. Luckily, during my first period of fieldwork I had already laid the foundation for a potential remedy to this problem. Namely, I had inquired into the possibility of meeting the interviewees for a follow-up interview during my next visit to Riga (cf. Murray and Wynne 2001, 165). All had replied positively to this request. When I got back, though, many were unable to meet with me; some were too ill, one had recently been transplanted, one had too much to do at work, and, sadly, one had passed away. Even so, of the thirteen patients I interviewed during my first visit I managed to meet six for a follow-up interview. For these occasions I had prepared individualised interview guides that covered the themes I wanted to delve deeper into. As my fieldwork progressed I also developed my skills in minimising the loss of details by lingering longer than I normally would on subjects of interest. Including the six follow-up interviews, I performed thirty-one interviews in total in Riga.

Translations

Between my three fieldwork periods in Riga the interpreters translated the interviews they had participated in – except for five that I did with the assistance of Katrina K. during my second visit, which were translated by Katrina G. and Ilze. None of them had ever done such translations before, but Katrina K. and Katrina G. both had jobs on the side of their studies involving translations.

Both during and after my first period of fieldwork in Riga, Katrina K. and I had long conversations concerning the transcriptions and translations. She sent me fragments of interviews that she had translated which we chatted about via Skype. The challenge we faced is apparent when one considers Borchgrevink's words: 'Translation involves interpretation and explanation of cultural context' (2003, 111). With this in mind, we felt it was necessary for the cultural context – which emerged, in the translation process, in the form of particular idiomatic expressions and descriptions of historically and culturally rooted practices and phenomena – to be deducible from the translated transcripts that Katrina sent to me, at least in the cases where it had had a major impact or was ambiguous. In order to accomplish this without disturbing the flow of the text too much we decided on a method in which Katrina used the comment function in Microsoft Word to communicate the problems she had faced and the way she had solved them. The method was subsequently communicated to and applied by Katrina G. and Ilze. This way of communicating the difficulties of translation was not always sufficient; some problems required face-to-face discussions, and for this we used Skype.

Since I speak Swedish, my analysis of the interviews I performed in Stockholm did not require that I translate them in their entirety. I had to translate the sections I cite in this book, of course, and this was occasionally challenging for much the same reasons as the interviews performed in Riga. However, due to my fluency in both Swedish and English, I had a greater sense of how culturally specific idioms and practices could be transferred between the two languages. In the end, the main difference between the interviews performed in Latvia and those performed in Sweden was that in the former context, I relied on the translated versions of the interviews to conduct the analysis in the first place. In Sweden my analysis preceded the translation and was therefore based directly on the interviews as they were transcribed. But the fact remains that all excerpts from the interviews that I cite in this thesis have been subject to translation. In order to increase the readability, I have edited them lightly, correcting the grammar and reformulating phrases that would be incomprehensible in writing.

The analytic process

My analysis of the empirical material began before I had collected all the material. Throughout my fieldwork I listened to the audio recordings and read the transcripts of the interviews and observations, continually relating these to my research questions and methods. There was thus a constant dialogue and interplay between my empirical findings, on the one hand, and my research objectives, methods, and theoretical points of departure, on the other. The analytic process of the study was characterised by a continual oscillation between presence and distance, between being in the field, processing what I learned there, relating this to the scientific points of departure, reworking these, and heading back into the field again (cf. Ehn and Löfgren 1996; Alftberg 2012, 27).

But the main analytical work began when the entire body of empirical material had been collected. At this point, I began reading all the material through several times, taking notes and, after a few read-throughs, identifying a number of overarching themes, which subsequently came to correspond roughly with the chapters of the thesis. I then colour-coded the segments of the transcribed interviews and observations that corresponded with these themes. Then a more focused phase commenced, where I focused on each of the identified themes separately, identifying sub-themes, based on which I made separate documents containing summarised accounts of what each interview and observation revealed about it. This phase to a large extent paralleled the writing of the various chapters. In fact, during the entire process of writing, I constantly returned to the transcripts, rereading them and relating them to each other. The oscillation between presence and distance thus continued. In identifying the various themes and performing the actual analysis, previous research on patienthood, which I will present below, and writings in the field of phenomenology, which I discuss in the next chapter, were also essential. Along with the description of the phenomenological points of departure of the thesis that I give in the next chapter, I provide an account of my method of analysis as it relates to this theoretical approach.

Ethical considerations

I have already mentioned some of the measures I took during my fieldwork to ensure the ethical viability of the study. In both Stockholm and Riga I was required to apply for ethical approval of the study, which prompted me early on to consider and reflect on the sensitivity of the topic and the vulnerable position of the majority of the participants. The primary purpose of such ethical evaluations is to protect the research subjects and to consider ways in which the risks that the research exposes these persons to can be minimised and balanced in relation to the benefits that the study is expected to generate (cf. Hagen 2013a, 34–35).

There are several risks associated with the type of research performed in the present study. Ethnographic research in general exposes participants to a situation in which aspects of their lives become subjected to scientific scrutiny, a process over which they have minimal control and from which they stand to gain no obvious personal benefits (Hansson 2007, 28). In ethnographic research that involves persons who suffer from an illness and who depend on medical treatments for their survival, more dimensions are added. These are persons who are already, prior to their participation in the study, in a position of dependence. Most obviously, they depend on the willingness of their caregivers to provide adequate care, but they also depend on the sociopolitical circumstances that make the provision of such care possible at all. This is a position of dependence that can make it difficult to decline the invitation to participate in the study; one may worry that one's declination will affect the care provided. In the present study, this risk was particularly evident in Riga, where I relied solely on medical professionals to ask patients about their willingness to participate.

What also put the patients at risk was their very embodiment of an illness. As will become increasingly evident throughout this book, life-threatening illnesses such as kidney failure radically alter the sick person's life and expose him or her to the risk of premature death. These may be difficult subjects to discuss in an interview. They may evoke insights and emotional responses that the interviewee is unprepared for. Observations are ethically precarious for similar reasons, as I have discussed to some extent above. The sick persons who were subject to my observations were not only fettered to a machine and unable to move during the treatment, they were also constantly at risk of experiencing severe physical reactions in the form of, for instance, drastic blood pressure drops, cramps, or fatigue. Thus, the conditions of the interaction between the participants and me could change rapidly during the course of an observation, especially at the units in Stockholm where I interacted more closely with the patients.

My presence as a researcher in the clinical setting also to some extent put the medical professionals, and particularly the nurses that I observed more closely, in a vulnerable position. Care professions are themselves of an ethically difficult nature, since the measures taken to diagnose and treat disease not infrequently risk violating the integrity and dignity of the sick person (cf. Young 1997). To have an outsider observing and documenting one's endeavours to balance this occasionally thin line may therefore be unpleasant. Similar feelings may emerge in the interview situation, where one may experience one's professionalism to be under evaluation rather than under a more open-ended scientific scrutiny.

Throughout my study I took various measures to minimise the above-mentioned risks. As I have already noted, I obtained informed consent from all the persons I interviewed and, at the units in Stockholm, from all the patients who participated in my observations. The letter that accompanied the consent form briefly described my study and the nature of my research methods.[12] It also mentioned the participants' right, at any time and without any justification, to discontinue their participation; the research material gathered as a result of this person's participation would then be destroyed. The letter also stated that participants' identities would be kept strictly confidential. To ensure this confidentiality, no real names are used in this thesis; all of the participants have been given pseudonyms.

Since the information about the study that was given in the letter accompanying the informed consent form was brief, I always supplemented it with an oral explication of the study, either when I obtained the participant's informed consent or at the beginning of an interview, before the recorder was turned on. I also encouraged participants to ask me questions, and they often did. In general, my ambition was to be as transparent as possible. At all three units in Stockholm, for example, I introduced the study and myself to the entire staff before initiating my fieldwork. During the study I also continually reminded the participants of their right to either discontinue their participation or tell me to stay away when they did not want me near. In addition, I tried to exercise constant perceptiveness towards the participants' emotional and bodily state during the observations and interviews. For example, I did not approach a patient if he or she seemed to be in distress or, for that matter, if he or she was deeply immersed in a book or a crossword puzzle.

To a certain degree these measures remedied some of the deficiencies of the informed consent procedure. By striving to take into account the circumstances of the particular situation in which an observation and an interview took place, I wanted to reduce the impact of the presumption inherent in informed consent procedures 'that all subjects weigh information and make "informed" choices similarly, and that they "voluntarily" participate with similar expectations' (Hoeyer and Hogle 2014, 352). Through this approach I also endeavoured to ensure the protection of the research participants beyond the temporal limitations of the informed consent, which tends to isolate the ethical responsibility of the researcher and the decision making of the prospective participant to a particular and

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[12] The letter was translated into Latvian, Russian, and Swedish to ensure that the participants understood the content.

clearly delimited point in time (Hoeyer and Hogle 2014, 354; see also Karlsson 2008; Gunnarson and Lundin 2015).

This work did not end when my fieldwork ended but extended into the writing process. As Alftberg points out, when one selects a group of people as research subjects on the basis of an already existing categorisation – be it age, sex, class, or disease – one risks participating in the reproduction of this categorisation, although the aim of one's study is to question and nuance it (2012, 25). In my writing, therefore, I have strived to destabilise and problematise the categories to which the participants are assigned by emphasising the situational, context-bound, and complex nature of the stories and practices studied.

Destabilising and problematising assigned categories also requires a reflexive awareness of oneself as a researcher and person (see e.g. Ehn and Klein 1994). Akin to Bremer, I want to characterise my research as a form of 'embodied ethnography' which acknowledges the mutual presence in the research context of the researcher and the participants as experiencing bodies (2011, 57–58; see also Turner 2000). When this embodied presence of researcher and participants is taken into account, the complexity of their interaction becomes clear; not only is it always situated in a particular context, it is also fundamentally shaped by the verbal and non-verbal messages that the involved bodies convey – about such diverse subjects as age, sex, class, health, mood, and personality – as well as the prereflective conceptions sedimented deep into the bodily layers of researcher and participants both. Although, in a phenomenological sense, I endeavoured to reflect on and thereby rid myself of my preconceptions, meeting the field as open-mindedly as possible, the fact that I entered the context of haemodialysis and kidney transplantation as an embodied human being with a particular perspective and particular objectives made accomplishing a completely unbiased approach impossible. It was not only my embodied presence during the observations and interviews as a healthy, relatively young, Swedish man that shaped the interaction between the participants and myself; so too did my presence as a researcher, creating a hierarchy between me and the participants and orienting my attention in some directions rather than others (cf. Ehn 2009, 41). In summation, then, although attaining a completely transparent research position is virtually impossible, I have endeavoured to maintain a reflexive stance towards myself and my study throughout the research process that resulted in this book.

Previous research on patienthood

This section intends to position the present study within a relevant research context and spell out the contribution that it aims to make to this particular context. Since patienthood is a central theme of this thesis, I have used it as a kind of unifying concept in my effort to identify a relevant research context. This does not mean that I have included only studies that are explicitly and elaborately patient-centred. This would have been much too narrow a scope. Studies that focus on other actors or investigate medical practice more generally often also contribute greatly to an increased understanding of patienthood. Consequently, I have included such studies too.

I do not place the present thesis within a research context that includes all scholarly exploration of patienthood. Since it is an ethnological study, utilising an ethnographic methodology, I have chosen to position it within a context predominately made up of research from within such fields as ethnology, (medical) anthropology, (medical) sociology, science and technology studies, and, to some extent, philosophy. I begin by applying a rather narrow focus, outlining previous research on patienthood in organ transplantation and dialysis specifically. I then broaden my scope in successive steps to include research on patienthood in relation to medical technologies more generally and to personhood and chronic illness.

Patienthood in organ transplantation and dialysis

As I have already mentioned, the social scientific and humanistic research on organ transplantation has tended to focus quite narrowly on the transplant event and the sociocultural and political dimensions governing the transfer of organs from donors to recipients. Although this has meant that the full complexity of what it means to live with organ failure and be dependent on various organ replacement therapies has been left almost entirely unaccounted for, this research constitutes an essential contribution to the study of patienthood within contemporary biomedical practice. Most importantly, it illustrates how efforts to tame the transformative nature of organ transplantation and to ensure a sufficient supply of transplantable organs have imbued organ-failure patienthood with a particular and fundamental normative charge.

In their influential book *Spare Parts: Organ Replacement in American Society* sociologists Renée C. Fox and Judith P. Swazey detail the development of organ transplantation from an experimental to a routine medical therapy and the subsequent emergence, in the 1980s, of what was and still is generally conceived of as an 'organ shortage' (1992, xvii). As an increasing number of patients were deemed eligible for the procedure, the shortage of organs emerged as the greatest challenge for transplant medicine. In an effort to overcome this challenge the metaphor of the 'gift of life' was borrowed from the blood industry and attached to the act of donating an organ. Although it is increasingly contested, the idea that an organ should be voluntarily donated and viewed as a life-saving gift has continued to govern the exchange of organs worldwide to this day (Gunnarson and Svenaeus 2012).[13] As Fox and Swazey illustrate, however, this gift is not one given and received completely freely. Drawing on Marcel Mauss's seminal work on gift exchange, they reveal the existence of an obligation not just to give but also to receive a donated organ (see also Schweda and Schicktanz 2012). They write, 'Great reluctance or outright refusal to accept the life-saving gift that is offered symbolically implies a rejection of the donor and of the donor's relationship to the recipient' (Fox and Swazey 1992, 35). But they find, in accordance with Mauss's gift exchange model, that this obligation extends even further, to include also the requirement to repay and reciprocate the received gift – an obligation, it turns out, that organ recipients find virtually impossible to fulfil, which prompts Fox and Swazey to coin the term 'the tyranny of the gift' (1992, 40).

In the social scientific and humanistic research on organ transplantation that has followed, the tyrannous character of the gift of an organ has been

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[13] The exception is Iran, where a regulated commercial market in organs has been introduced (see Ghods and Savaj 2006).

recurrently reasserted. Building further on the work of Fox and Swazey, a central theme of this research has been the transformative nature of organ transplantation. By means of an ethnographic methodology, several scholars have found that, following transplantation, organ recipients often struggle to depersonalise the body part they have received, experiencing the presence of the donor inside their body (Sharp 1995, 2006; Lock 2002; Sanal 2011; Shildrick 2012, 2013). For many, this is a radically transformative experience, altering not only their sense of self but also their kinship ties, prompting worry about who the donor might have been, spurring a desire to seek out the donor kin, or, in the case of living donation, transforming the character of already established relations. As anthropologist Lesley A. Sharp (1995, 2006) has asserted, this is so despite the fact that transplant professionals prescribe a view of the transplanted organ as a lifeless object merely replacing a lost bodily function (see also Lock 2002; Shildrick 2012). Sharp thus shows us that another obligation – on top of the obligation to receive and repay – is added to organ-failure patienthood, namely the duty to objectify the received body part. However, many organ recipients fall short of fulfilling this obligation, too, which several scholars attribute to the powerful social, symbolic, and embodied vitality with which human organs tend to be charged (Lock 2002; Waldby 2002; Shildrick 2012). But Sharp also ascribes this shortfall to the inherent contradictions characterising the 'transplant ideology' that governs transplant professionals' actions (1995, 2006). While, at one end of the organ transfer chain, recipients are told that the organ they have received is merely a biological entity filling a particular bodily function, at the other end of the chain, Sharp contends, the donor kin are given an image of the donated organ as retaining a trace of the donor's personality, which persists after it has been transplanted into the recipient's body.

Another contradiction characterising the transplant ideology that Sharp (1995, 2006) identifies concerns the concept of brain death and is eloquently captured by Margaret Lock (2002) in the title of her book *Twice Dead*. In their respective studies, Sharp and Lock show how not only the kin of a deceased potential organ donor but also the medical professionals themselves frequently find the beating heart and warmth of the brain-dead body to be deeply troubling. And as anthropological work on organ procurement in countries such as Germany (Hogle 1999), Japan (Lock 2002), Egypt (Budiani 2007), and Turkey (Sanal 2011) has illustrated, this is experienced as troubling not just on an individual level, but also at national and religious levels. As these studies so convincingly demonstrate, death and the dead body are far from universal phenomena, and neither is the biomedical science underlying the concept of brain death on which transplant activities rely.

All of the above-referenced works, and especially those focusing on the receiving end of the organ transfer chain, constitute valuable contributions for understanding organ transplant patienthood. But unlike most of them, which tend to be concerned mainly with the events taking place and the experiences of the involved actors in conjunction with the very giving and receiving of organs, in the present study I am primarily interested in what it is like to live with a transplant. I direct my attention towards the 'life', rather than the 'gift', aspect of the 'gift of life' metaphor. I am interested in what promises about life are attached to this metaphor and how these promises affect haemodialysis patients' views of and orientations towards organ transplantation and haemodialysis. In my efforts to accomplish this goal, a number of studies have constituted valuable sources of inspiration. Among these, there are some that highlight the promissory rhetoric characterising the public and academic discourses on organ transplantation. Anthropologist Megan Crowley-Matoka, for example, contends that organ transplantation is generally 'imagined to restore health in a fairly straightforward way, analogous to simply replacing a faulty motor part' (2005, 822). Framed in this manner, anthropologist Ciara Kierans (2005, 345) points out, transplantation becomes conceived of as an 'end game', as the end of an extended struggle against disease. Thus, what is promised through this rhetoric is both an escape from organ-failure patienthood and a return to a healthy and normal life.

As Sharp (2006) and Siminoff and Chillag (1999), among others, argue, the 'gift of life' metaphor and the focus on the need to overcome the 'organ shortage' characterising lay and medical discussions of organ transplantation serve to reinforce this view of the procedure, thereby concealing the various hardships associated with it. After transplantation, several studies have shown, organ recipients generally struggle to achieve the promised health and normality, finding themselves instead '"betwixt and between" the roles of "sick" and "healthy", "patient" and "normal person"' (Crowley-Matoka 2005, 822; see also Siminoff and Chillag 1999; Amelang et al. 2011). Due to the need to promote organ donation, the image of transplantation as a straightforward normaliser and bringer of health has to be maintained, an endeavour into which recipients inevitably become drawn. As a consequence, yet another obligation is added to organ-failure patienthood, namely the requirement to describes oneself as living a healthy and normal life following transplantation, even though one does not experience that to be the case (Sharp 2006; see also Amelang et al. 2011).

Although all of these works provide valuable insight into what it might be like to live with a functioning transplant, most of them reveal fairly little about the events that transpire prior to transplantation and, even more so, after the transplant has ceased to function. Kierans (2005) and Sanal (2011) to some extent thematise the relationship between disease, dialysis, and transplantation among kidney failure patients in Ireland and Turkey, and Crowley-Matoka (2005) provides a brief description of how Mexican kidney failure patients learn to desire a transplant through the pervasive rhetoric mentioned above. But none of these works thoroughly investigate themes such as the process of falling ill with kidney failure, the practice of haemodialysis, and the experience of returning to dialysis after having lived with a functioning transplant, themes that I aim to address here.

There are some studies that explore the practice of dialysis and the experiences of dialysis patients more thoroughly. Gordon (2001) tries to answer the question of 'why dialysis patients refuse offers of living donor kidneys'. Hamdy (2009) explores Egyptian haemodialysis patients' cultivation of spiritual acceptance of their situation. Åhdal (2012) interviews transplant recipients about their experiences, prior to receiving a transplant, of managing haemodialysis by themselves at home. Russ, Shim, and Kaufman (2005) study the experiences of elderly patients on dialysis, while Idvall and Lundin (2009) explore elderly dialysis patients' experiences of being on the waiting list for kidney transplantation and being faced with the alternative of receiving an organ from a so-called marginal donor. Taken together, these studies help me in my endeavour to piece together a more cohesive and inclusive understanding of kidney-failure patienthood.

Patienthood and biomedical technologies

In this section I broaden the scope and position the thesis within the context of social scientific and humanistic research on biomedical technologies more generally. There is extensive social scientific and humanistic research on biomedical technologies, and in what follows I do not purport to consider this entire field. Rather, I highlight research that I have found to be particularly relevant for an exploration of the theme of patienthood.

As I have already indicated, one of the basic presuppositions that guide my inquiry is derived from research that emphasises the interrelationship between biomedicine as a science and biomedicine as a technology. Here I am inspired not only by anthropologists Lock and Nguyen, who draw on Ludwig Fleck to argue that 'biomedicine itself is a technology' (2010, 11), but also by the more philosophical orientation of Don Ihde (1993). According to Ihde, 'Modern Science' has from its very inception been experimental, and has therefore relied on material instruments to reach scientific objectivity (1993, 72). As a consequence, he argues, science should be viewed as a '*technologically embodied* […] *specialized praxis* among other such praxes of human activity' (Ihde 1993, 76, emphasis in the original). The intertwinement of science, technology, and practice that Ihde acknowledges constitutes a basic point of departure for my study. This intertwinement has been highlighted and explored through ethnographic inquiry by many anthropologists and ethnologists (see e.g. Thompson 2005; Lock and Nguyen 2010). For example, in a study about the gradual routinisation in clinical practice of what is called therapeutic plasma exchange (TPE) – a medical therapy that replaces patients' plasma by circulating their blood through a machine – anthropologist Barbara A. Koenig (1988) illustrates that the introduction of this new scientifically infused technology not only altered medical practice, but the very scientific development of the technology itself hinged on its implementation in practice. In the beginning, when the technology was still considered experimental, a technician was present to assist the doctor in carrying out the treatment. Later, when it had become routine, the nurses took over, while the doctors only attended treatment sessions when their research interests motivated them to do so.

As I indicated earlier in this introductory chapter, I am also inspired by research that views biomedical technologies as simultaneously embedded in and disembedded[14] from particular local and national settings (see e.g. Franklin 1997; Thompson 2005; Mol 2008; Lock and Nguyen 2010; Beck 2012). What this research illustrates is that, on the one hand, in constituting standardised material instruments developed to treat bodies that are seen to be everywhere the same, biomedical technologies gain a transnational reach. Around them, particular practices are developed that remain more or less intact across national borders. On the other hand, these technologies and their implementation in practice never remain unaffected by the particular social, historical, cultural, political, and material contexts in which they are practiced. To a varying extent and in varying ways, this research demonstrates that the particular local or national setting in which a biomedical technology is practiced shapes what it comes to be and how it comes to be experienced.

As Franklin (1997) and Beck (2012), among others, point out, in always already being simultaneously embedded and disembedded, biomedical technologies are never universal. Rather, they always originate from particular sociomaterial research contexts which shape what they become, but which also underlie the very motivations that bring them into being in the first place. This has led several scholars to conclude that technologies in general and biomedical technologies in particular are inherently non-neutral, meaning that they are both productive and reproductive of norms and values (see e.g. Ihde 1993; Lock and Nguyen 2010; Sharp 2014). In highlighting and exploring this moral and normative charge of biomedical technologies, social scientific and humanistic research in the field of what are called assisted reproductive technologies (ARTs) have been particularly inspirational to me (see e.g. Franklin 1997; Lundin 1997, 2012b; Thompson 2005). These studies demonstrate the simultaneous conservative and

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[14] Here I use the term disembedment in Anthony Giddens's (1991) sense of the term. Giddens describes 'disembedding mechanisms' as 'the "lifting out" of social relations from local contexts and their rearticulation across indefinite tracts of time–space' (1991, 18).

transformative character of such technologies, which simultaneously reproduce the normality of desiring a child and produce new notions of kinship. These studies also – as was the case with the research on organ transplantation – address the promises and hopes attached to biomedical technologies. While transplantation promises health and normality, ARTs promise normality in the form of a 'take-home baby' (Franklin 1997, 94).

Several social scientific and humanistic scholars have highlighted the power of biomedical technologies to redirect patients' – or perhaps, rather, persons' – lives. Anthropologist Sharon R. Kaufman (2005) highlights the forceful imperative of movement built into the American intensive care practices, while Koenig (1988) demonstrates how a 'technological imperative' takes form as a result of the routinisation of TPE. Yet, as Mol asserts, 'technologies are unruly' (2008, 50); they do not have predictable outcomes and thereby govern us as much as we govern them.

Taken together, the social scientific and humanistic research on biomedical technologies noted above highlights the complexity of the situation that patients are thrown into when they come into contact with such technologies. As a patient, one becomes a participant in a technoscientific practice infused with norms and values that both transform and promise the retention of certain taken-for-granted conceptions, actions, and desires. In the present study I intend to contribute to the understanding of this complexity by employing a phenomenological theoretical framework to examine two intimately related but decidedly different biomedical technologies – one considered unremarkable and deficient, and the other spectacular and successful.

Patienthood, personhood, and chronic illness

In what follows I broaden my scope even more and attempt to position the study within a research context that thematises patienthood more generally. Being a patient involves more than interacting with technologies. It also entails participating in care practices, interacting with health professionals, inhabiting particular spaces, belonging to a particular group of people, and so on. The complexity at work here becomes even more evident when one looks up the word 'patient' in a dictionary. According to the *Oxford English Dictionary* (2015) the word patient has four general meanings: a person admitted to a medical facility of some sort, a person who suffers (preferably without complaint), a person who or thing which is the passive recipient of some action, and a person who exercises patience. Thus, semantically the word patient includes bodily, spatial, temporal, and interactional dimensions.

I have found anthropologist Katharine Young's (1997) book *Presence in the Flesh: The Body in Medicine* particularly helpful in the process of grasping this complexity. In the book Young provides a phenomenologically and ethnographically grounded definition of patienthood – which I will discuss thoroughly in chapter 5 – and argues that a person's transformation into a patient involves a shift in focus through which the person's body comes to be viewed as an object rather than a subject. Young is careful to point out, however, that this transformation does not take place in a sociocultural vacuum. Inspired by phenomenologists such as Maurice Merleau-Ponty, she sees the body as inextricably intertwined with its surroundings, and therefore conducts a thorough analysis of the spatiotemporal, material, and interactional dimensions of a person's transformation into a patient. Young does not, as I do, explore patients' experiences of illness and patienthood. Nor does she study the care provided to the chronically ill or discuss the clinical setting in terms of an institution. For me, therefore, Young's definition and exploration of patienthood constitutes a kind of starting point, from which I depart, but which I also modify and build on further.

Another study that has constituted a valuable source of inspiration for my exploration of the enactment and negotiation of patienthood in haemodialysis and kidney transplantation is ethnologist Lars-Eric Jönsson's (1998) study of the care of the mentally ill in Sweden between 1850 and 1970. By means of extensive archival material, and with a particular focus on the spatial dimension, Jönsson explores how the mentally ill patient was constructed in the care practiced during this period. Although he advances spatiality as the most important dimension, he also highlights the interactional, bodily, and, unlike Young, the institutional dimensions of patienthood (see also Magnússon 1996). In contrast to Young, who is mainly concerned with primary care, Jönsson studies a form of patienthood that totally engulfs the ill person once he or she is admitted to the care institution. My study positions itself somewhere in between these two studies, since it explores a form of patienthood that penetrates deep into the sick persons' lives but is not all encompassing. Like Young, Jönsson does not perform a thorough analysis of the patients' experiences of mental illness and patienthood. He is prevented from doing so by his use of archival material.

As the definition of the word patient above illustrated, a patient is always an embodied person. It is a person who suffers, gets admitted to a medical facility, becomes the passive recipient of someone else's actions, and exercises patience. This becomes even more evident in chronic conditions, in which patienthood becomes a permanent aspect of a person's life, of his or her personhood. There is extensive social scientific and humanistic research on chronic illness, and it is beyond the scope of this section to consider all of it. Rather, in what follows I will position the study in relation to a few influential works and studies that have been particularly important for my research endeavours. From the early 1980s onwards a number of studies were published that emphasised the importance of highlighting the sick person's perspective and activity in living with and managing a chronic condition (cf. Barbot 2006). One such study was Strauss et al.'s (1984) book *Chronic Illness and the Quality of Life*, which first came out in 1975 but was republished in a revised and extended version in 1984. In this book, Strauss et al. stress the importance of viewing chronically ill persons as active subjects and taking account of the complex work these persons do to manage and come to terms with their illness in their everyday lives. Like some of the studies that followed in its wake (see e.g. Kleinman 1988; Charmaz 1991, 2000; Toombs 1992), the study by Strauss et al. highlights the ways in which persons who fall ill with a chronic illness become forced to reorganise their lives, how they have to actively find new ways of performing the everyday actions that make up their personal, family, and working life.

A primary focus of this and more recent studies (see e.g. Charmaz 1991) has been the temporal dimensions of living with a chronic condition. These studies show how time becomes an issue for persons who live with an unpredictable sick body, not only because of the body itself but also because of the temporality of the various actions that have to be directed towards it. In their ambition to highlight the perspective of the sick person, however, several of these studies (see e.g. Strauss et al. 1984; Toombs 1992; Charmaz 2000) make too clear-cut a distinction between patienthood and personhood, between the medical view of and actions directed at the sick person, on the one hand, and the sick person's own perspective and ways of managing the condition, on the other. In the present thesis, I explore the interaction between these two realms and ways of being in the world and investigate how and in what situations they influence each other.

I share this ambition with several scholars (see e.g. Kleinman 1988; Hansson 2007). I have for example found studies that thematise and problematise the experience of receiving and living with a medical diagnosis interesting (see e.g. Forss et al. 2004; Hansson 2007; Drakos and Hydén 2011; Hagen 2013b). These studies show that diagnoses do not remain within the medical context but accompany diagnosed persons into their everyday life, affecting them in various, context-bound ways. Another field of research that addresses the intertwinement of the realm of medicine and the realm of the sick persons' everyday life is research on ageing and old age. Here, two studies by Swedish ethnologists have influenced me. Eva M. Karlsson (2008), for example, discusses ways in which the home has become increasingly conceptualised as an ideal place of care, while Åsa Alftberg (2012) addresses the transformation of the home, and of the old person as an embodied being, that is effected by the things of a medical nature which enter the realm of everyday life in old age.

This touches upon another field of research that has contributed greatly to my own research endeavours, namely the study of what is generally referred to as 'self-care' and the morally and normatively charged form of patienthood that underlies the increasing provision of such care. Starting in the late 1990s, numerous studies have been published that attest to the emergence of new ideals concerning patienthood. According to these ideals, it is argued, patients should no longer be passive receptors of health professionals' actions but be active consumers of care (Barbot 2006; Rose 2007; Alftberg and Lundin 2012) who make informed choices (Hansson 2006; Mol 2008) and who are seen and treated by their caregivers as autonomous, responsible, and empowered, whole persons (Rose 1999; Kaufman 2005; Hansson 2007; Fioretos 2009; Idvall and Lundin 2009). Patients should be afforded the means necessary to exercise flexibility and control (Fioretos 2009) and be seen as experts of their own body and care (Lundin 1997; Novas 2006), and furthermore, despite suffering and poor prospects, they should think positively (Wilkinson and Kitzinger 2000) and retain a grain of hope (Delvecchio Good et al. 1990). These ideals have been linked in some studies to the increasing neoliberalisation of societies worldwide (see e.g. Fioretos 2009; Alftberg and Hansson 2012), a connection that I highlight and explore in this thesis.

A brief foray into neoliberalism

I would like now to linger for a while with these processes of neoliberalisation and give a brief account of their history and contents. 'It is possible to identify a worldwide neoliberal turn in the 1970s,' Johanna Oksala writes (2013, 53), referring to the elections of Margaret Thatcher and Ronald Reagan as heads of state in Britain and the United States, the appointment of Paul Volcker as chairman of the U.S. Federal Reserve, and the steps taken by Deng Xiaoping to liberalise China's economy as decisive events, all of which took place at the very end of the 1970s (see also Harvey 2005, 1). But as a political economic theory, neoliberalism has existed considerably longer. According to Michel Foucault (2008), neoliberal thought dates back to the late 1940s and the economic research that was conducted at the Freiburg School in post-war Germany and the Chicago school of economics in the United States.

Although the theoretical concepts and ideas that were formulated within these schools of thought have had a great impact on the policies launched worldwide in the name of neoliberalism from the 1970s onwards, it is important, David Harvey points out, to pay attention to the complex tension that exists between neoliberalism as a theory and neoliberalisation as it is actually taking place in various geographical locations (2005, 19). That this is so becomes particularly evident when one considers the diverging ways in which neoliberalism has become a political and practical reality for persons worldwide during the last decades. Not only is there currently 'an uneven geographical development of neoliberalism' globally, Harvey contends (2005, 13), but the ways in which and the contexts into which its policies are actually applied also vary greatly. Extensive anthropological research has shown, for example, how the neoliberal 'shock therapy' that the majority of post-Soviet countries underwent in the wake of the collapse of the Soviet Union has had a variety of complex and context-bound outcomes. Contrary to the 'transition theories' advanced by influential economists, who saw the post-Communist countries as entering an inevitable transition towards a Euro-American style of market economy after shock therapy, ethnographic research has illustrated that neoliberal policies and reforms do not remain unaffected by the particular sociocultural and political circumstances present in the national and regional settings into which they are implemented (Buyandelgeriyn 2008). Latvia, for example, has been said to have entered into a more unconstrained form of neoliberalism than many of its post-Communist neighbours since it gained independence from the Soviet Union in 1991 (see Bohle and Greskovits 2007), while Sweden, according some commentators, has undergone a gradual neoliberalisation during recent decades and is currently displaying a 'circumscribed' form (Harvey 2005, 156).

Indeed, as Foucault demonstrates, the belief that neoliberalism would be capable of providing the foundation for an entirely new state was what oriented the endeavours of the Freiburg School back in the 1940s. The only legitimate ground on which to found a German state after the ravages of Nazism, they argued, was a completely freed market. The state that would thus be formed would have as its main purpose to ensure that no constraints were put on the market (Foucault 2008, 82–85). This was one of the ways in which neoliberal thought differed from classical liberalism. Contrary to the liberalism developed with inspiration from Adam Smith, among others, the neoliberal state was to be an active one, always at work on developing ideal conditions for a free market (Rose 1999, 144; Foucault 2008, 145). This is why, contrary to what many neoliberals would openly admit, the state constitutes an important aspect of neoliberal governing (Harvey 2005, 21).

What the neoliberal theorists from the 1940s onwards opposed were policies of state intervention aimed at market mechanisms – Keynesianism, for example (Harvey 2005, 20). Such interventionist policies had oriented political action during the first half of the twentieth century, and the neoliberals saw this as one of the main reasons for the emergence of fascism in the 1930s (Rose 1999, 137; Foucault 2008, 116). The neoliberal reforms that have been launched from the 1970s onwards, therefore, have entailed a gradual withdrawal of the state from the economic realm. Despite the existence of substantial geographical differences, this withdrawal has generally taken the form of a deregulation of markets, a privatisation of state assets, a maximisation of economic growth, an enhancement of competition, a removal of state-funded social safety nets, a flexibilisation of the labour market, and an abandonment of employment rate in favour of inflation as a measure of economic success (Harvey 2005; Foucault 2008).

But since economy, within neoliberalism, is 'understood as the rationality of the entirety of human action' and not just of the market, it is not only the economy that should be set free, but also the individuals that act within it (Oksala 2013, 67). 'The assumption that individual freedoms are guaranteed by freedom of the market and of trade is a cardinal feature of neoliberal thinking,' Harvey writes (2005, 7). As such, it emerges as a 'political ontology' (Oksala 2013, 67) or 'ethic in itself' (Harvey 2005, 8) that is productive of a particular form of subjectivity. This subject is one that autonomously, responsibly, and rationally engages in his or her own self-actualisation by making informed choices based on an economic logic of costs and benefits. It is an enterprising, atomic, and self-interested individual who actively seeks to realise him- or herself but who can expect little assistance in this endeavour on the part of the state (Rose 1999, 137–145; Foucault 2008, 222–230; Oksala 2013, 66–70). In other words, through 'a double movement of autonomization and responsibilization' (Rose 1999, 174),[15] the neoliberal subject is at once set free to work on him- or herself and made responsible for the outcome of this work.

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[15] Even though Rose (1999) writes about the emergence of neoliberal thought in the 1940s and the implementation of neoliberal policies in the 1970s, he does not himself use the term neoliberalism. Instead, he coins the term 'advanced liberal' (Rose 1999, 139–140). It is not completely clear why he sees the latter term as more apt at explaining the societal processes he describes. But as I interpret his writings, what he wants to get at is the difference between neoliberalism as a theory and neoliberalisation as it is actually taking place in particular Western societies. Hence, he has the same ambition as Harvey. But since Harvey manages to make this distinction without coining a new term, my aim is to do so too. Therefore, when I refer to Rose's writings in the chapters to come I solely use the term neoliberalism to denote the societal processes he describes.

It is specifically the impact of this neoliberal production of a particular subjectivity on the patienthood enacted in renal replacement therapy that interests me in this thesis. But, as we have seen above, this production is in no way separated from the actual neoliberal reforms implemented on national and transnational levels. Throughout the thesis I therefore endeavour to follow Harvey's recommendation to attend to the tension between neoliberalism as a theory – or as a set of ideals – and neoliberalisation as it is actually implemented and practiced.

Outline of the dissertation

The chapter following this is also a form of introductory chapter, giving a thorough account of the theoretical points of departure of the thesis. The aim of the chapter is not only to give the reader a comprehensive description of the primarily phenomenological theories that I employ, but also to position the study within and contribute to the cultural analytical engagement with phenomenology in general. I end the chapter with an elaboration of the analytical methodology that this theoretical approach results in.

In chapter 3, my exploration and analysis of the empirical material commence. From this chapter on, the thesis is structured in a way that corresponds roughly with the chronology with which most persons afflicted with kidney failure encounter and live with the disease and the two treatment alternatives. But unlike the structure of this book, which has a definite end, kidney failure patients' interaction with and dependence on renal replacement do not; for as chapter 7 – the chapter that precedes my concluding discussion – establishes, persons who have experienced both treatment alternatives soon find themselves in a form of spiralling circularity where the two therapies supplant each other.

To return now to chapter 3, in which I explore the events that takes place when persons with kidney failure move towards patienthood. This chapter begins by offering a thorough analysis of the events that transpire before renal replacement therapies are initiated, paying particular attention to the participants' experiences of falling ill and being diagnosed with kidney failure. I then go on to explore their first encounter with the two treatment alternatives, highlighting the moral and normative charge of these. The next chapter, chapter 4, details the nature and interrelation of three modes of coping that persons with kidney failure use in order to emotionally and existentially handle their embodiment of the disease and dependence on the two therapies.

In the following two chapters, chapter 5 and 6, haemodialysis is the focus of the analysis. While chapter 5 explores the practice of haemodialysis, chapter 6 moves out of the treatment setting and directs its attention towards the life that the participants live when they are away from the unit. In the exploration of the haemodialysis practice that I conduct in chapter 5, I pay particular attention to the forms of patienthood that are enacted here and attempt to discern how the patients as embodied persons figure into this. In doing so, I study the actions carried out, the objects used, and the interaction taking place between patients and medical personnel during the treatment. In chapter 6 I direct my attention towards the ways in which kidney failure and haemodialysis enter the daily lives of the participants. I explore the work that they do to make this life liveable and highlight the significance of their experiences as patients for the life they come to live as persons.

In chapter 7 I pick up where I left off in chapter 3 and continue my discussion of kidney transplantation. Here, however, my focus is on the participants who have already undergone one, two, or even three transplants. I explore the ways in which their experiences of undergoing transplantation and living with a transplant affect their orientation towards both treatment alternatives. In doing so, I highlight the complexity, contingency, and multiplicity of kidney transplantation.

In the chapter that ends the thesis, chapter 8, I summarise the main findings of the book and discuss some of its more general implications.

2. A cultural phenomenological analysis of haemodialysis and kidney transplantation care

As the subtitle of this book, and even more so the title of this chapter, indicates, I consider the present study to be a cultural phenomenological analysis of haemodialysis and kidney transplantation care (cf. Frykman 2012). In what follows, I attempt to explain what I mean by this. I begin with a brief discussion of the concept of culture, which I relate to and combine with my phenomenological points of departure. My aim in doing so is not just to describe what a cultural phenomenological analysis might be, but also to position the thesis among recent ethnological studies that employ a phenomenological framework. To a certain extent, this is a continuation of the review of previous research that I did in the previous chapter, but one focused entirely on research that employs a phenomenological approach. I then go on to give a thorough account of the phenomenological points of departure that orient my analyses throughout the thesis. The aim of this account is both to lay the foundation for my subsequent analyses and to contribute to the cultural analytical engagement with phenomenological theories in general.

The concept of culture

In anthropological and ethnological writings, culture is often described as a 'slippery' and hard-to-use concept (Lock and Nguyen 2010, 6; Frykman 2012, 19). Ingrid Fioretos (2009) argues that this is mainly due to the fact that it has come to be used – in academic writings and in public discourse – as a way of ascribing totalising and static features and traits to individuals and groups of people. When such an essentialist understanding of culture is coupled with place, which Fioretos points out is often the case, the people who inhabit a particular place, be it a country, region, or suburb, may be ascribed certain behaviours and perceptions. But the reverse can also be the case; the way a person acts and perceives the world may be explained by his or her cultural belongingness (Fioretos 2009, 19). The 'culturalism' that is the result, Lock and Nguyen (2010, 8) argues, makes it possible for individuals and institutions to direct their attention away from the social, economic, and political dimensions of a person's situation, ascribing his or her behaviour solely to a static and totalising culture.

Among anthropologists and ethnologists today, however, there is a widespread consensus that cultures are not unchanging and totalising superstructures, fully determining our behaviours and conceptions. Quite the opposite, cultures are seen as dynamic, processual, situational, and relational, and the persons inhabiting them as both bearers and producers of them (see e.g. Ehn and Löfgren 2001; Fischer 2007; Fioretos 2009). Conceptualised in this manner, cultures are understood as deeply situated in the daily practices of our lives, as reproduced or altered by our everyday actions, and as involving the materiality of the things we use and the spaces we inhabit (see e.g. Hansson 2007; Alftberg 2012). What makes a culture a culture, however, is that the ideas, norms, values, and patterns of actions of which it consists are shared by a group of people, small or large (Ehn and Löfgren 2001). But these elements are never shared once and for all. Rather, they depend on the very sharing that takes place in the practices that produce and reproduce them. This does not mean that cultures are characterised by constant fluctuations and changes. Indeed, to be a culture, its ideas, norms, values, and patterns of actions must be shared for some time. Such tenacity is not just a product of the individual will of the involved actors, but is also to a large extent due to the relations of power[16] that permeate cultures and to the routinisation and habituation of actions and conceptions. As cultural beings, anthropologists and ethnologists tend to argue, we are

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[16] Here, ethnologists and anthropologists generally use some version of a Foucauldian concept of power, highlighting its relational, variable, and productive nature. Power in this sense does not coincide with a particular individual or institution but denotes 'a complex strategic situation in a particular society' (Foucault 1990, 93).

shaped by the cultural contexts that we inhabit and therefore come to view some, rather than other, actions and conceptions as normal and natural (Ehn and Löfgren 2001; Fioretos 2009; Lock and Nguyen 2010).

In the present thesis, I subscribe to this view of culture, and I do so because it allows me to situate the actions, views, and experiences that I study in dynamic and complexly configured interlacements of cultural processes on local, national, and transnational levels. It enables me to study the complex interplay between and intertwinement of these levels in the very practices and interview accounts that constitute my empirical material (cf. Fioretos 2009, 18). Doing so is particularly important at a time when the universal claims of the natural sciences in general and the medical sciences in particular are gaining an ever-greater influence over our lives; when the materialisation of these claims as care practices engages and reshapes our bodies in new and fundamental ways, and when the ways our bodies react to these practices are measured against a universal human body (cf. Koenig 1988; Lock and Nguyen 2010; Svenaeus 2013).

I have found it particularly fruitful to combine this cultural analytical approach with a phenomenological one. As ethnologist Jonas Frykman (2012) points out, phenomenology directs our focus towards how human beings bodily and practically inhabit the world, towards how our embodied inhabitance of a particular world orients us in certain directions and towards particular objects, objectives, and others. What I find phenomenology particularly apt at showing is how cultural processes sediment and incorporate themselves deeply into our bodily existence, while at the same time never completely depriving us of our unique bodily perspective. In other words, from a phenomenological perspective, cultures are often deeply and prereflectively shared, but never completely shared. As Frykman contends, a phenomenologically inspired cultural analysis enables us to study the enactment of culture, to explore how cultural processes are produced and reproduced, and how human beings become part of or excluded from them (2012, 19).

In relation to the particular theme of my research, this is especially important because I am interested in how persons with kidney failure manage and experience their altered bodily existence and their integration in the normatively charged cultural practices studied. As we shall see below, from a phenomenological viewpoint, the human body is more than a biological entity; it is what makes our existence possible in the first place, that which allows us to inhabit a world. As such, our existence as cultural beings hinges on our embodiment. But the reverse is also true: it is by being born into an always already cultural world that we are able to find our way. Consequently, when our bodies fail or change drastically, so too does our being in the world. What I am interested in here is how such drastic alterations affect persons' embodied inhabitance of the world, and how and what bodily and cultural resources are mobilised to manage it.

In utilising such a phenomenological framework, I do not have the intention, as Frykman (2012) does, to contrast my study against research concerned with discourses and representations. As I see it, phenomenology must concern itself with such matters too, albeit in another way than purely discourse analytical studies. In his ambition to highlight the constitutive power of human embodied action, Frykman downplays the importance of discourses and representations, portraying them as an effect of the former. This is not necessary; one does not have to choose one over the other. On the contrary, phenomenology gives us unique access to the complex and constitutive interplay between bodies, things, representations, discourses, spaces, and so on. A central question of the present study, for example, is how persons manage the encounter with their bodies as representations in the form of diagnoses or test results.

Attempts have been made in several ethnological studies to combine a phenomenological approach with a Foucauldian one (see e.g. Ljung 2001; Hansson 2007), with the primary aim of adding analytical tools capable of capturing processes of power found to be wanting in phenomenology. To a certain degree, I enact a similar combination, taking inspiration, for instance, from scholars drawing on Foucault's theory of governmentality. I am mainly inspired, however, by theorists who highlight the potential of phenomenology itself to account for and critically scrutinise structures of power and norms (see e.g. Weiss 1999; Ahmed 2006; Malmqvist and Zeiler 2010). Several studies have recently been published within Swedish ethnology that employ a similar approach (see e.g. Bremer 2011; Alftberg 2012; Göransson 2012). These have all constituted valuable sources of inspiration for the present study. I now move on to give a thorough account of the phenomenological points of departure that guide my analyses throughout this thesis.

The lived and absent body

Phenomenology is not a homogeneous theoretical formation. Since its birth, in the philosophy of Edmund Husserl, it has evolved in a number of directions. In the present study I make use of a number of writings, from different time periods, which to a varying extent have their roots in phenomenology. Some originate in the field of philosophy, others in ethnology, anthropology, and cultural studies. Some deal with human existence in general, while others more specifically turn their attention towards themes such as health, illness, and medicine. Thus, even though I make use primarily of theories from one tradition, what I present below is an eclectic mixture of theoretical concepts which I have found productive in relation to my empirical findings.

I would like to turn first to the phenomenological concept of the lived body. The term 'the lived body' (*Leib*) was coined by Husserl in the beginning of the twentieth century, and famously developed by French philosopher Maurice Merleau-Ponty[17] (2002) in his book *Phenomenology of Perception*, first published in 1945. In my account of the concept of the lived body below, my main point of departure is in this work.

The body is lived, phenomenologists argue, because it is as bodies that we get access to and project ourselves into the world. If it were not for the 'sensorimotor powers' of the body, there would not be a world for us (Leder 1990a, 5). It is through our perceptual organs and our ability to move that we come into contact with the objects and others around us. Our being-in-the-world[18] is not a causal effect of these bodily functions, how-

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[17] Merleau-Ponty had several terms for the lived body; for example, *corps propre* and *corps vécu*.

[18] The term being-in-the-world (*In-der-Welt-sein*) has its roots in Martin Heidegger's (2010) philosophy and denotes the way in which human existence is already from the outset situated in, or thrown into, a world. Inherent in this 'being-there' (*Dasein*), as Heidegger calls it, is also our capacity as human beings to reflect on, to understand, our own existence.

ever, but the result of a meaningful encounter between body and world. Perception is not a 'primitive function', Merleau-Ponty argues, but a 'system of meanings which makes the concrete essence of the object immediately recognizable, and allows its "sensible properties" to appear only through that essence' (2002, 13, 151). Thus, when we perceive an object, we do not understand it by attending to its 'sensible properties', but rather through the immediate process by which these properties are filtered through a 'system of meaning'. But how does such a system of meaning come about?

To answer this question we need to turn to Merleau-Ponty's version of the psychological concept of 'body schema'.[19] For Merleau-Ponty, this concept denotes the simultaneous process by which the body coordinates its different parts and comes to have a world (2002, 273). Thus, 'the body schema, as Merleau-Ponty understands it, is an implicit awareness that is rooted in motility, and by virtue of which the lived body simultaneously forms a whole and aligns itself with its surroundings' (Malmqvist and Zeiler 2010, 137). It is this synthesis of the body and its inextricable entwinement with the world that gives rise to the system of meaning on which every act of perception relies. The meaning is therefore neither in the world nor in the body, but in their encounter (Merleau-Ponty 2002, 157). It is moreover practical and prereflective rather than intellectual and thematised (Malmqvist and Zeiler 2010, 137). By virtue of our bodily being-in-the-world, a familiarity with objects and others is achieved which precedes our intellectual thematisation of them. We do not have to analyse the spatial structure of a coffee cup in order to know what to do with it. The purpose of the cup and the movements required for drinking from it are known in advance. The coffee cup has a meaning for the person drinking from it that goes beyond the sheer sensible properties of it. Rather than being something with such and such height and colour, the cup presents itself as something meant to drink coffee from. This means that the bodily movements required for taking a sip from the cup are also part of its meaning (Merleau-Ponty 2002, 164). In other words, accompanying the meaning of an object are always intentions. Merleau-Ponty writes:

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[19] I also use the term 'corporeal schema' to denote this concept.

> The life of consciousness […] is subtended by an 'intentional arc' which projects round about us our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects. (Merleau-Ponty 2002, 157)

As embodied beings engaged in a world, our intentionality necessarily situates us. The 'intentional threads' that our bodies throw out provide the situation we are in with meaning (Merleau-Ponty 2002, 150). But the reverse is also true: our intentions essentially derive from our situation. As embodied beings, we have a past and a future, and we always find ourselves in a 'physical, ideological and moral situation'. The meaning that is projected around us therefore cannot be separated from the historical and cultural context within which we reside in a given situation. This is particularly evident when Merleau-Ponty develops the concepts of incorporation and habit.

Before elaborating on these two concepts I would like to turn to what philosopher Drew Leder has called 'the absent body' (1990a). Proceeding from the phenomenological concept of the lived body, Leder argues that insofar as the body is our lived connection with the world, it necessarily recedes from our attention. When, for instance, we look at something, what we see is not our own seeing, but a certain meaningful object. The same applies to all of our perceptual and motor organs. When we hear, we hear *something*, when we walk, we walk *somewhere*, when we touch, we touch *something*, and so on. Our attention is always directed *from* our body *to* the surrounding world. Without this 'from–to' structure, Leder argues, experiencing the outer world would be impossible (1990a, 15). It is easy to see, for example, that if I were to attend to every muscular movement required for drinking coffee, there would not be a lot of coffee going down my throat. This is why Leder writes of the absent body. Since it is by means of the lived body that we have access to the world, it must necessarily recede from our attention.

But neither world nor body is static. The situation of the body in the world is constantly subject to change. The body schema, therefore, is a fundamentally dynamic structure. It is a malleable and 'open system', capable of incorporating new objects and abilities into its prereflective and practical being-in-the-world (Merleau-Ponty 2002, 163–170). When Merleau-Ponty develops the concept of incorporation, he gives the famous example of the blind man's stick. For the blind man, he argues, the stick is no longer an object. It is a part of the perceptual and motor powers with which he, as an embodied being, extends into and becomes engaged with the world. When he perceives things with it, he does not have to make explicit the length of the stick, he is immediately aware of the positions of objects through it (Merleau-Ponty 2002, 165–166). Incorporation thus transforms a person's body schema, creating new 'perceptual and motor possibilities' for his or her engagement with the world, and comprises the disappearance from his or her attention of the incorporated object (Malmqvist and Zeiler 2010, 140). In order for the blind man to orient himself in his surroundings, the stick must cease to be an external object and instead become a new mode of perception for him. The incorporation of an object therefore necessarily involves its receding into the perceptual and motor repertoire of the absent body with which we project ourselves into the world.

This brings us to the issue of habit. In Merleau-Ponty's understanding, habituation and incorporation presuppose each other. They are both essential constituents of the process by which the body schema rearranges and renews itself (Merleau-Ponty 2002, 164–165). Acquiring a habit necessarily involves the incorporation of something that was initially not a part of one's prereflective and practical bodily engagement with the world. But at the same time, in order to incorporate an object, one has to become familiar with it. One has to grow accustomed to it to the extent that one attends to what it allows one to do rather than to the way it is used, and such familiarity can only be the result of a process of habituation (Malmqvist and Zeiler 2010, 142–143). In the vast majority of cases, though, habituation does not take place in isolation. Sometimes there is someone there giving instructions; on other occasions there are persons present whose use of the object in question one may observe (Leder 1990a, 31). The ways in which we habitually incorporate external objects are thus to a great extent intersubjective and steeped in a cultural form.

But it is not only material objects that may be subject to habituation and incorporation. A person learning to dance can also be said to incorporate something (Merleau-Ponty 2002, 165). Unlike the blind man's stick, the dance is not in the world as a material object but rather as a kind of 'practical logic' which the dancer eventually, through practice, incorporates into his or her corporeal schema (Malmqvist and Zeiler 2010, 142). When the dancer has learned the new dance, he or she has added a new skill, rather than a new thing, to the perceptual and motor repertoire with which he or she is engaged in the world (Leder 1990a, 30–32). In their article 'Cultural Norms, the Phenomenology of Incorporation, and the Experience of Having a Child Born with Ambiguous Sex', Malmqvist and Zeiler (2010) take things even further. They argue that, along with material objects and immaterial skills, cultural norms can also be incorporated. As embodied beings situated in a cultural context, we incorporate conceptions and practices shared by the people around us. We habituate 'cultural patterns of understanding and action' until they disappear from our attention and become part of our practical and prereflective engagement with the world (Malmqvist and Zeiler 2010, 143). Consequently, when incorporated, cultural norms 'belong to that *from* which we make sense of the world, act, and interact, and thus rarely present themselves as that *to* which we direct our attention' (Malmqvist and Zeiler 2010, 144). As is the case with material objects, the incorporation of cultural norms transforms our body schema, and hence our being-in-the-world.

The distinction between material objects and cultural norms that I make here is problematic, however. As numerous scholars before me have shown, not least in the fields of ethnology and anthropology, and as my own empirical data illustrates, material objects are not free from cultural meanings (see e.g. Hansson 2007; Lock and Nguyen 2010; Alftberg 2012). Indeed, this is also what Merleau-Ponty teaches us. How we perceive and make use of the objects around us depends on the system of meaning generated through the inextricable entwinement between body and world. Therefore, when a material object is incorporated, so are its cultural meanings.

The oriented body

According to Merleau-Ponty, 'Consciousness is being-towards-the-thing through the intermediary of the body' (2002, 160). As conscious beings, we are not only embodied, but we are also necessarily oriented. We are directed towards the thing by means of our embodiment. This was implicitly evident already in my account of the lived and absent body above. Drawing on Leder, I argued that our bodily being-in-the-world relies on a from–to structure by means of which we are directed from our bodies towards the surrounding world. But I also showed that this directedness is never random or arbitrary. It is essentially a result of our situation. Our embodied engagement with the world always carries with it a history and takes place within a cultural context. However, it is not only the world around us that is subject to change; so too are the prereflective, practical, and absent bodily resources by means of which we inhabit it. As I argued above, our corporeal schema is dynamic. It is capable of habitually incorporating material objects and immaterial skills as well as cultural norms. Thus, in addition to the worldly conditions provided by our current situation, our orientation also relies on the bodily resources that we have habitually incorporated. Rather than being the *result of* our situation, our orientation therefore *is* our situation. The historicity and the 'physical, ideological and moral' conditions at work in a given situation are not something external to our bodies. Through habituation and incorporation we come to acquire an embodied history on which our orientation relies every moment. Merleau-Ponty writes:

> Since it cannot be oriented 'in itself', my first perception and my first hold upon the world must appear to me as action in accordance with an earlier agreement reached between *x* and the world in general, my history must be the continuation of a prehistory and must utilize the latter's acquired results. (2002, 296)

What Merleau-Ponty refers to here when he writes of an 'earlier agreement between *x* and the world in general' is the body schema. Since we are always already bodily 'at work in a world', we acquire from the beginning an embodied history that orients us in subsequent situations (Merleau-Ponty 2002, 295). Our inherence in the world necessarily shapes us as embodied beings. Our experiences 'sediment' into our bodily resources by means of which we orient ourselves in future situations (Merleau-Ponty 2002, 150; Ahmed 2006, 54–56). Consequently, as Sara Ahmed so poignantly points out in her book *Queer Phenomenology*, 'Orientations are organized rather than casual' (2006, 158). They are the result of the repetition of some directions more than others. Since we are always already inhabiting an intersubjective world, there are always already orientations taken. The world is from the outset oriented, and we 'find our way' in it by aligning ourselves with the 'collective "lines"' that are already there (Ahmed 2006, 1; Malmqvist and Zeiler 2010, 143). And when we are 'in line', our point of view as well as the line itself vanishes from our attention. Ahmed writes, 'We follow the line that is followed by others: the repetition of the act of following makes the line disappear from view as the point from which "we" emerge' (2006, 15). To use the vocabulary of Merleau-Ponty, the line becomes incorporated into the prereflective, practical, and habitual bodily repertoire through which we get access to and project ourselves into the world.

Orientations and lines are thus intimately related. According to Ahmed, lines are the accumulation of points of view taken as a product of our orientation. In taking certain points of view for granted, in being oriented, we simultaneously align ourselves with and reproduce particular lines. As such, a person's alignment or misalignment with a particular line is not neutral. Since orientations and lines are organised rather than casual, our being-in-the-world is characterised by 'the political requirement that we turn some ways and not others' (Ahmed 2006, 15). Lines are thus fundamentally normative (cf. Bremer 2011, 41). By aligning ourselves with dominant, collective lines, we also align ourselves with and reproduce pervasive norms. But not all human beings are able or willing to align themselves with dominant lines. Due to the interdependence of bodies and lines, the bodily resources of which our corporeal schema consists determine which lines we can follow. But the reverse is also true: the lines we follow shape us as embodied beings.

The persistence of lines relies on repetition. For a line to persist, embodied persons[20] have to repeatedly orient themselves in its direction. Lines

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[20] Throughout the thesis I generally use the term 'person', rather than 'self' or 'subject', to denote human, embodied existence as it is understood within phenomenology. In doing so, I intend it to have the same meaning as the two latter terms.

are thus not static (Ahmed 2006, 15). Nor are all of them aligned with pervasive norms. By means of the work of repetition, embodied persons who cannot or will not align themselves with dominant lines may create alternative – or 'oblique or diagonal' as Ahmed (2006, 61) calls them – lines, through which they orient themselves alternatively in the world. For this reason, ethnologist Michelle Göransson suggests, the lines that intersect in or as a particular society or situation should be seen as a 'web [...] in which some threads are thicker and more persistent while others are almost transparent, self-dissolving' (2012, 26, my translation). Being oriented in the direction of an alternative line is a more precarious endeavour than following a thick line repeated by many. Irrespective of what kind of line one follows in a particular situation, however, to be oriented, in Ahmed's sense of the term, is to be an embodied person who aligns him- or herself with a line in such a way that he or she prereflectively understands and feels at home in the world, and directs him- or herself outwardly towards the objects and others of that world. Depending on the pervasiveness of the line, though, the intensity of the feeling of homelikeness that it produces may vary.

How, then, should one understand our orientation towards the objects of the world? As I argued above, our intentional movements towards an object are necessarily part of its meaning. When I reach out to take a sip from the coffee cup in front of me I prereflectively and practically 'define' it. Thus, the way in which we are oriented towards an object affects what it comes to be. But Ahmed takes things a little further. She argues that it is our orientation that determines what objects we come into contact with in the first place. 'I can perceive an object only insofar as my orientation allows me to see it,' she writes. And in order to see the object 'it must be near enough to me' (Ahmed 2006, 27). The fact that I have a coffee cup in front of me is therefore not a coincidence but a result of the particular orientation that I have taken. Being oriented, then, is to be directed towards some things rather than others.

Our encounters with objects do not leave us unaffected. The nearness of certain objects, our orientation towards them, and the things they allow us to do shape us as embodied beings. Not only do they allow us to extend into the world in certain ways, but they also reproduce or alter the orientation we have already taken (Ahmed 2006, 15, 27). To illustrate this, Ahmed uses the example of the objects surrounding the writing philosopher. She writes:

> The nearness of the philosopher to his paper, his ink, and his table is not simply about 'where' he does his work and the spaces he inhabits, as if the 'where' could be separated from 'what' he does. The nearness of such objects is required by his work, which is also 'what' he does for a living. (Ahmed 2006, 55)

Becoming a writer or a philosopher requires the nearness of certain objects. Studying what objects are near a person and how that person makes use of them may therefore tell us something about who that person is.

It should be clear by now that orientations are essentially both spatial and temporal. As embodied beings, we necessarily have a 'here' and a 'now'; we must always be 'where' and 'when' our bodies are. But this does not mean that we are '*in* space, or *in* time', Merleau-Ponty writes (2002, 161). As an embodied being, I do not float around in space and time totally unaffected by them; 'I belong to them, my body combines with them and includes them' (Merleau-Ponty 2002, 162). Our orientation in a given situation relies on an embodied history of previous orientations. In order for us to perceive at all, our body has to be capable of sedimenting past experiences and habitually incorporating new objects, skills, and norms. Orientations therefore necessarily 'take time and require giving up time' (Ahmed 2006, 20). But orientations are also temporal in the sense that they are future-oriented. When we direct ourselves towards something, we aim at it both spatially and temporally, and do not know in what direction our encounter with the object will take us on this particular occasion (Merleau-Ponty 2002, 162; Ahmed 2006, 21). Since we inhabit time, it is not something external to our body, but an essential feature of our being-in-the-world.

The same applies to our relationship with space. 'Space is not the setting (real or logical) in which things are arranged, but the means whereby the position of things becomes possible,' writes Merleau-Ponty (2002, 284). As I have already mentioned, in order to perceive something, we have to be directed. We have to live from our bodies towards the surrounding world.

Insofar as we have such a direction, things will appear to have certain positions. They will be near or far, left or right, high or low, and so on. Some things will perhaps be so far away or seen from such an unusual angle that we do not understand what they are. Other objects, conversely, will appear right in front of us at a distance that allows us to grasp their meaning. Thus, it is because space is lived, because it is inhabited, that things come to have their positions. But the reverse is also true; it is the position of things that determines how we extend into space and whether the direction we have already taken becomes altered or is reproduced (Ahmed 2006, 14). Ahmed writes, 'Space acquires "direction" through how bodies inhabit it, just as bodies acquire direction in this inhabitance' (2006, 12). But since orientations are organised, neither the orientation of our bodies nor the orientation of space is casual. The way things are arranged around us is an effect of the repetition of some directions more than others.

Dys-appearance

In my elaboration of the phenomenological concept of the lived body so far I have shown how consciousness is embodied and outwardly oriented, how our access to the world relies on our being bodies that attend to the things around us rather than to ourselves as bodies. I have also addressed the fundamental situatedness of our embodied being-in-the-world, and shown how our orientation relies on our inherence in an intersubjective world with historical depth. What I have yet to discuss, however, is the lived body as an object, as a thing of flesh and blood, as something that can be seen and touched, and might break down. This simultaneous subjectivity and objectivity of the body is essential since it is what enables us to inhabit and perceive a world in the first place (cf. Zeiler 2010). For example, without perceptual organs such as eyes, ears, hands, and legs, we would not be able to see, hear, touch, or move. Nor would it be possible for others to be with us. It is essentially by means of our bodily appearance and movements that we are recognised by others. But it is also through this bodily materiality that we may attend to our own bodies. Although we are ordinarily outwardly directed, the thingness of our own body enables us to orient ourselves towards it, to attend to our own body as an object.

To illustrate the complexity that is at work when we attend to our own bodies, Drew Leder uses the famous phenomenological example of the right and left hand touching each other. ‘When my right hand reaches out to touch, I “exist” it as a power of sensing. I do not attend to the hand as physical thing but employ it as that through which I explore the world,’ Leder writes (1990a, 14). When touching his left hand with his right, the right hand is absent from his attention, while the left hand is the object to which he directs it. Leder, then, poses the rhetorical question whether or not letting the left hand touch the right hand would allow him to ‘capture at one and the same moment the right hand as touching and touched’ (1990a, 14). But the answer must be no since the right hand, when being what is touched, ceases to be part of the touching. From this, Leder states the following general principle: ‘Insofar as I perceive through an organ, it necessarily recedes from the perceptual field it discloses’ (1990a, 14). In other words, a person can attend to his or her body as an object of attention, but in doing so parts of it are always absent from this attention. The body is therefore different from all other objects in that it is that by which there are objects in the first place.

But matters are even more complicated than this. In writing about bodily self-awareness, Zeiler argues that, as embodied beings, we do not just occasionally orient our attention towards our body as a reflectively thematised object, but we are also constantly prereflectively aware of our body. What Zeiler means is that, although our body is generally absent from our attention, we are constantly prereflectively aware of it as our existential here and now, as the centre of our inhabitance of and engagement with the world. Thus, it is a different form of bodily self-awareness than the form described by Leder above. ‘The former’, Zeiler writes, ‘is prereflective; the latter is also reflective’ (2010, 334). The ‘also’ in the previous sentence is important since it indicates that one can also be prereflectively aware of one’s body as an object. This is so, for example, Zeiler writes, when one experiences pain that one does not reflectively attend to and which thereby does not disrupt one’s activities but merely prereflectively colours them. This does not mean that a reflective thematisation of one’s body as an object presupposes an alienation of the self from it. Although a distance between self and body is created in such instances, our reflective attention towards our body does not necessarily prevent us from experiencing it as being our own body (Zeiler 2010, 340). At stake in the simultaneous subjectivity and objectivity of the body, therefore, is not a contrast between 'mind and body, in which body is implicitly object, nor between subject and object, in which body is presumptively subject. The proper contrast is between body-as-self and body-as-object, and both of these are aspects of the experience of being a body,' as anthropologist Katharine Young (1997, 5–6) has so eloquently expressed it.

On some occasions, Leder points out, we have no choice but to reflectively attend to our body. Suddenly the from–to structure on which its absence relies is disrupted and we are forced to thematise it. This typically happens when we experience our body as something 'problematic or disharmonious' (Leder 1990a, 70). Leder's main examples for such situations are disease and pain. When we are struck with disease or pain, he argues, our body emerges from its absence and forces us to direct our attention towards it. Leder labels this state 'dys-appearance'. Characteristic of dys-appearance is that it originates from within the body itself. Something happens with the body that makes it appear for the subject as problematic and disharmonious. Unlike other modes of bodily appearance, therefore, dys-appearance exerts a particularly forceful 'existential demand' (Leder 1990a, 92). The body – or the part of it that hurts or does not function correctly – becomes impossible to ignore and may therefore 'be experienced as that which "stands in the way," an obstinate force interfering with our projects' (Leder 1990a, 84).

In her writings, Zeiler nuances the concept of dys-appearance.[21] She distinguishes between three versions of it. These denote:

> Situations where the subject is pre-reflectively aware of the body as bad or ill and where intentionality is threatened; situations where the subject is pre-reflectively and reflectively aware of the body as bad or ill and where intentionality is disrupted; and situations where the subject is pre-reflectively aware of the body as bad or ill and where she or he cannot attend to others or the body in a reflective way because of pain. (Zeiler 2010, 341)

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[21] Zeiler also introduces the concept of eu-appearance, which denotes occasions when the body appears as 'good, easy or well' (2010, 334).

As we can see, the distinctions Zeiler makes rely both on a distinction between prereflective and reflective bodily self-awareness and on an assessment of the extent to which the dys-appearance intrudes on a person's intentionality. Clearly, then, as long as intentionality is only threatened and not disrupted, the body may very well dys-appear without reaching the reflective level. But when intentionality is disrupted, the body inevitably emerges into reflective awareness. The reverse is also true. When, due to pain or disability, for example, the body suddenly emerges into reflective awareness, the person has no choice but to interrupt what he or she is doing and attend to it. The third and last version of dys-appearance that Zeiler distinguishes is pre-reflective since the severity of the bodily discomfort prevents the person from taking a reflective stance towards his or her body. Here, intentionality is not even mentioned, which is not so strange when one considers that this version concerns situations where 'one's whole self is nothing *but* pain' (Zeiler 2010, 337). When I write about dys-appearance in the following chapters I am mainly concerned with the first and second versions of the phenomenon.[22]

Unhomelikeness and disorientation

In view of what I have written above about the nature of the lived body and its inextricable entwinement with the world, it should be clear that an alteration of one's relation to the body, in the form of a dys-appearance, should give rise to a similar alteration of one's being-in-the-world. Or in other words, since a person's access to and engagement with the world relies on his or her being directed from the body rather than towards it, when the body is reflectively thematised, as in the second version of dys-appearance described above, the from–to structure on which a person's engagement with the world depends is disrupted. Drawing on the theories of Sara Ahmed and philosopher Fredrik Svenaeus, I will now take a closer look at such instances of disruption.

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[22] In doing so I mainly rely on an assessment of the extent to which an instance of dys-appearance disrupts a person's intentions.

Before doing this, however, I first wish to consider an important distinction which will be relevant from now on, namely that between disease and illness. This distinction was first elaborated by psychiatrist Leon Eisenberg and has since been used extensively by researchers from a vast array of academic disciplines. Simply put, the distinction differentiates between illness as a person's experience of being sick and disease as the biological 'it' which the doctor's diagnosis accomplishes. It is important to note that neither illness nor disease is isolated from the cultural context from which they emerge. They are both 'culturally shaped' (Kleinman 1988, 5) and enacted 'in common, day-to-day, sociomaterial practices' (Mol 2002, 6). Now, let us return to the disruptions of the bodily from–to structure that I promised to elaborate on.

As we saw above, the main concept in Sara Ahmed's writings is orientation. When we are oriented, Ahmed claims, we are aligned with the lines of which the world consists, and as a result of this alignment, we find our way, understand, and feel at home in the world. But Ahmed also introduces the concept of disorientation, which concerns the instances when a person is unable to align him- or herself with the world. Before exploring this further, I would like to turn to Fredrik Svenaeus's (1999) concepts 'homelikeness' and 'unhomelikeness', which he develops in his book *The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice*. Taking the phenomenology of Martin Heidegger as his main point of departure, Svenaeus attempts to answer the questions 'What is medicine?' and 'What is medical knowledge?' (1999, 15). In doing so, he also endeavours to define health and illness. Health, he contends, is a homelike being-in-the-world, while illness is an unhomelike being-in-the-world. Although, as mentioned above, Svenaeus mainly makes use of the theories of Martin Heidegger, we do not have to start from the beginning in order to account for the concepts he elaborates. Heidegger's and Merleau-Ponty's theories, namely, share some basic characteristics. They both understand human existence as being always already in the world. While Merleau-Ponty advances the notion of the body schema to illustrate this, Heidegger develops the concept of 'Dasein', which is 'the "being-there" of human existence' (Svenaeus 1999, 141). But *Dasein* also denotes our ability as humans to reflect on our own existence. Furthermore, for Heidegger as well as for Merleau-Ponty, the world is a '*meaning-structure*' which is not external to but is a result of our engagement with it (Svenaeus 1999, 142, emphasis in the original). Things, or 'tools' as Heidegger calls them, receive their meaning from our use of them, and all tools taken together form the 'totality of relevance' within which we act (Svenaeus 1999, 144). The being-there of *Dasein* is thus, as was the case with the lived body in Merleau-Ponty, an understanding existence (Svenaeus 1999, 148). Svenaeus writes, 'To understand, in Heidegger's phenomenology, is to find one's place in the meaning-structure of the world and project oneself towards possible goals' (1999, 149). Understanding for Heidegger, as for Merleau-Ponty, thus primarily concerns our prereflective and practical engagement with the world. And it is this engagement that takes us '*outside*' of ourselves, that enables us to transcend into and understand ourselves by means of the 'supra-individual structures of the world' (Svenaeus 1999, 146, emphasis in the original).

In Svenaeus's elaboration of the concepts of homelikeness and unhomelikeness, Heidegger's notion of transcendence plays a crucial role. Transcendence, here, denotes the fact that, as human beings, we always already inhabit a world, a world that is inseparable from our very being. This openness to and unity with the world is, according to Heidegger, achieved by means of three so-called 'existentials': understanding, attunement, and discourse. The three existentials are essentially intertwined. Our engagement with the world hinges on their interaction. But they can still be conceived of as three 'modes of being' (Svenaeus 1999, 145). As we saw above, understanding takes us outside of ourselves through our meaningful engagement with the world. But our understanding would not be meaningful if it was not already attuned through a number of moods and feelings. The attunement of our being-in-the-world, Heidegger argues, is what unifies it and affords us direction, and is therefore essential for our ability to find our place and feel at home in the world (Svenaeus 1999, 147). The third existential is discourse, or language, and designates the '*articulation* of the meaning-structures of the world' (Svenaeus 1999, 149, emphasis in the original). It is primarily through discourse that we are able to explicitly reflect on the nature of our existence, Heidegger contends.

From this understanding of human being-in-the-world, Svenaeus goes on to develop his theory of health and illness. In doing so, he gives the lived body the status of the fourth existential. In line with Merleau-Ponty's claim that it is only as embodied beings that we get access to a world, Svenaeus asserts that our embodiment is essential for our attuned and understanding being-in-the-world (1999, 184). But he also points out that as much as our existence belongs to the world, it necessarily belongs to our bodies. The biological processes of the body are not only essential for our being-in-the-world; they are also beyond the scope of our control. Simultaneously, however, only insofar as we are able to move our bodies and direct them in certain directions do we get access to and become capable of transcending into the world. As a consequence, 'the body is alien, yet, at the same time, myself' (Svenaeus 1999, 186). The same is true for the relation we have to the world. Since the world that we inhabit is from the outset intersubjective, historical, and cultural, we neither own it nor control it. But in our engagement with it, in our transcendence into it, we necessarily make it our own. Svenaeus writes, 'The world I live in is certainly first and foremost *my* world (and not the "objective" world of atoms and molecules), but to this very "mineness" also belongs otherness in the sense of the meaning of the world belonging to other people' (1999, 157, emphasis in the origina). It is in this simultaneous mineness and otherness of body and world that we find the potentiality for the unhomelikeness that Svenaeus claims characterises the experience of illness. But let us begin with his definition of homelikeness and health.

Being at home in the world, according to Svenaeus, means finding oneself and one's place in the world by means of an attuned understanding. It is residing within a world that is familiar since it is the setting into which one transcends (Svenaeus 1999, 155–157). In maintaining such a state, health is essential. Svenaeus defines health as 'a non-apparent attunement, a rhythmic, balancing mood that supports our understanding in a homelike way without calling for our attention' (1999, 159). Understood in this way, health is a mood from which rather than towards which we live. Akin to the body itself, it is absent from our attention. It is a mood that functions as a 'background attunement' which tacitly supports our understanding of the world and ourselves in it (Svenaeus 1999, 160). But it is also rhythmic and balancing, since it adapts itself to certain bodily alterations.

During our life span, our bodies change, we age, go through puberty, become pregnant, and so on. Such bodily alterations are not experienced as illness, but as natural shifts characteristic of the rhythm of life. For this to be the case, the 'non-apparent attunement' of health has to actively but tacitly balance itself (Svenaeus 1999, 159, 165). To sum up a little, one can say that health as a homelike being-in-the-world is a continuous process that serves to keep distant the inherent otherness of body and world.

It is this otherness that is brought to the fore and that makes us lose our sense of being at home when we fall ill, Svenaeus argues (1999, 157). Illness is unhomelike since it limits our ability to transcend into the world with our attuned understanding intact. Svenaeus writes, 'The dizziness, pain and annoyance [experienced in illness] colour and determine the understanding of the ill person, who is thrown back on himself as an obtrusive burden, rather than thrown into the world of the others.' When we fall ill, our transcendence becomes '*defective*' and incoherent; it no longer extends us into the world in a meaningful way (Svenaeus 1999, 163 , emphasis in the original); we are thrown back at our bodies and forced to scrutinise them as though they were not the medium through which we inhabit the world. But this does not mean that illness affects only the fourth existential – the meaning-structure made up by the body – but, since all four existentials are inextricably intertwined and always presuppose each other, illness necessarily affects the sick person's entire being-in-the-world (Svenaeus 1999, 186). 'The unhomelikeness of illness is consequently a certain form of senselessness, an attunement, of, for instance, disorientedness, helplessness, resistance, and despair,' writes Svenaeus (1999, 192–193).

It is interesting that Svenaeus, in the sentence just quoted, uses the word disorientation to characterise the unhomelike being-in-the-world of illness, since this is the word used by Ahmed to describe similar experiences. For Ahmed, disorientation denotes the occasions when we lose our place and our way in the world, when the objects around us no longer extend our reach, and when the orientation of space does not align with the orientation of our bodies. Thus, when we are disoriented, our engagement with the world diminishes, and rather than being a lived and outwardly directed embodiment, we become objects in a world experienced as 'oblique' (Ahmed 2006, 159–162). Ahmed's concept of disorientation clearly echoes many of the features of Svenaeus's concept of unhomelikeness, and the other way around. They are both about the failure of transcendence and the loss of one's prereflective and practical understanding of and engagement with the meaning-structures of the world. Indeed, for Ahmed, becoming disoriented necessarily means losing the familiarity of one's home. Disorientation makes homes 'queer', she writes (Ahmed 2006, 176).

What sets the two concepts apart, however, is their scope. Although it is clear, in Svenaeus's (1999, 194) characterisation of the concept, that illness is not the only form of unhomelikeness, it is to describe illness that he uses it – and so too do I in this thesis. In relation to unhomelikeness, disorientation should therefore be understood as a more general term, denoting the loss of one's way and place in the world in general. Consequently, one can conclude that when a person experiences an unhomelike being-in-the-world in the form of illness, he or she is always disoriented. But as we shall see in the coming chapters, and as Svenaeus himself contends, illness always afflicts an embodied person who inhabits a world, and therefore frequently gives rise to other forms of disorientation. Unhomelikeness is ordinarily intimately intertwined and in constant interplay with other forms of disorientation.

The process of falling ill

Before moving on to describe how the theoretical points of departure presented above take shape as a method of analysis, I want to consider some more phenomenological perspectives on illness and disease. There are several phenomenological writings that explore the process of falling ill, describing how the bodily alterations taking place in illness affect our being-in-the-world (see e.g. Leder 1990b; Toombs 1992; Svenaeus; 2009). Since these detailed explorations provide valuable insights for my analyses in the coming chapters – especially the next one – I will remain with them for a while in what follows.

In their analyses of the process of falling ill, both Toombs (1992) and Svenaeus (2009) divide the events that take place into several stages. Inspired by Sartre, Toombs distinguishes four stages, while Svenaeus, inspired by Sartre and Toombs, distinguishes five. For both of them the 'pre-reflective experience of discomfort'[23] constitutes the first. This stage is interesting since it reveals the deep intertwinement between the embodied self and the world. Here, illness is experienced prereflectively, which means that the person falling ill does not thematise it as illness or even as having to do with the body at all, even if the body prereflectively dys-appears. Rather, it is ordinarily experienced as belonging to the particular activity that the person is involved in, or to the world itself (cf. Alftberg 2012). Sartre's famous example is of a person with a headache reading late at night. Initially, the headache does not show itself as such, but as an increasing difficulty in focusing on and following what is written. At this stage, the illness is located in the person's prereflective and practical being-in-the-world, which might explain why the world itself may also be experienced as strange or uncomfortable. If the person puts down the book and lies down for a while or goes to make a cup of tea, the discomfort may, at least temporarily, go away (Svenaeus 2009, 56).

But if it does not, and the body begins to dys-appear, the process of falling ill has entered the second stage in Svenaeus's model – this is the stage that Svenaeus adds to Toombs's model – which he terms 'lived, bodily discomfort' (Svenaeus 2009, 60). This stage is also to a certain extent pre-reflective, since it precedes the person's thematisation of the body as ill, in the form of 'distinct thoughts and hypotheses' (Svenaeus 2009, 62). But instead of residing only in the activity or in the world, the discomfort is now felt in the body, and the body in its entirety – or, more commonly, one or more body part(s) – emerges as a 'problematic and disharmonious thing' (Leder 1990a, 70). This is where the 'process of alienation', which Svenaeus argues commences when a person falls ill, begins to be experienced by the sick person (2009, 58). This process is alienating since the body turns up for the embodied self as a thing 'with a life of its own', which is 'other but yet mine' (Svenaeus 1999, 58). In other words, in illness the body is undoubtedly mine, otherwise I would not experience the discomfort and pain, but it is also clearly not mine, since it is beyond my control and since there is an 'I' experiencing an 'it' that is painful or otherwise problematic.

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[23] Toombs terms this stage 'pre-reflective sensory experiencing' (1992, 31).

As Leder points out, this process of alienation is captured also by the term dys-appearance, where the prefix 'dys' might mean not only '"bad", "hard", or "ill"' but also '"away", "apart", or "asunder"' (Leder 1990a, 84, 87). The body that appears in dys-appearance is thus, to a certain extent, away or apart from – that is, alien to – the self that embodies it. But this is the case also in health. Not even when we are healthy do we control the biological processes that make our existence possible; we are embodied by our body as much as we embody it (Svenaeus 1999, 185–186). But we tend not to experience our body as alien, since it is ordinarily absent from our attention. One can thus infer that the alienation process that Svenaeus has in mind is not one in which the body actually becomes increasingly alien, but rather one in which the person embodying the body experiences it as increasingly alien. One can also infer that this heightened awareness of the alien nature of the body is paralleled by a process of enhanced awareness of the body as an object. In 'lived, bodily discomfort' the body turns up as some*thing* that hurts and prevents *me* from doing what I want to do. Falling ill thus entails experiencing a mutual process of bodily alienation and objectification.

According to Svenaeus, each stage in the process of falling ill brings this alienating process 'to a new qualitative level' (2009, 62). In the next stage, 'suffered illness', the body is therefore experienced as even more alien. Svenaeus does not write much about this stage, but he implies that this is where the bodily discomfort reaches the reflective level and becomes thematised as illness. Fortunately, Toombs's discussion provides some more details. She first offers a set of conditions that have to be fulfilled in order for the process of falling ill to reach the stage of 'suffered illness'. She writes, 'If the immediate experience of bodily disruption is sufficiently unusual, prolonged, uncomfortable, and so forth, then it must be explicitly attended to by the patient and reflected upon' (Toombs 1992, 33–34). The lived, bodily discomfort preceding this stage thus has to be of a certain character. Moreover, as Svenaeus implied, 'suffered illness' is characterised by a reflective awareness on the part of the sufferer of the 'bodily disruption'. But what makes this an illness experience, according to Toombs, is the person's intuitive understanding that 'the symptoms are part of a large whole' (1992, 35).

This might prompt the person who is falling ill to visit a doctor, at least in a context where biomedical care is available and culturally recognised. Before doing so, however, the person might have some theories about what disease he or she is suffering from. Such ruminations bring the person to the fourth of the five stages, 'disease pondering'.[24] To reflect on a suffered illness in terms of disease is an increasingly widespread way of interpreting and managing illness, especially in contexts where biomedicine constitutes the primary mode of diagnosing and treating bodily ailments (Toombs 1992, 36).

This is not the stage at which the world that the person falling ill inhabits enters the illness process for the first time. That has already happened. Since an embodied person is always indissolubly intertwined with the world, cultural processes are already at work in the first stage of the process of falling ill. As we saw above, illness first emerges in the activities we are engaged in, but its emergence is also itself affected by what we do: if we put down the book we are reading, the initial signs of illness may disappear. As Ahmed (2006) shows, the activities we engage in both result in and are the result of the orientations we take, orientations which are organised rather than casual – that is, directed by norms and values which materialise through the repetition of some directions more than others. What we do in the world – which might be influenced by our nationality, ethnicity, class, and gender – affects how illness enters into our lives. By pointing this out, I want to emphasise the fact that even though the existence of cultural and individual differences tends to become visible for the first time when the person falling ill reaches the reflective stages in the process, they are already there from the start.

If the person who is falling ill decides to visit a doctor, and in the event that he or she receives a diagnosis, then his or her illness becomes thematised as a particular 'disease state', which constitutes the final stage in Svenaeus's and Toombs's models. In the 'disease state' the patient's illness becomes conceptualised in scientific and biomedical terms as a 'pathological and pathophysiological process', which is most often provided with a name, a diagnosis (Toombs 1992, 39). In contemporary biomedicine, disease and diagnosis are thus intimately linked (Drakos and Hydén 2011, 18).

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[24] Toombs simply terms this stage 'disease' (1992, 35).

The stages in Toombs's and Svenaeus's models of the process of falling ill are clearly to be understood as chronological. But they also have a logical relationship, Svenaeus argues, in that they presuppose each other. He writes, 'You can only suffer illness if you first have suffered lived, bodily discomfort; and you can only suffer lived, bodily discomfort if you have already suffered pre-reflective experience of discomfort (Svenaeus 2009, 62). This applies, at least, to the first three stages. It is possible, Svenaeus points out, to go into stage four – 'disease pondering' – or stage five – 'disease state' – directly. He illustrates the first scenario with an example of a woman whose sister has been diagnosed with breast cancer and who is aware of the fact that the disease to some extent has a genetic basis. The woman now starts disease pondering; she searches her breasts for lumps and undergoes a diagnostic test. The second scenario occurs when a person receives a medical diagnosis without having experienced any of the first four stages. This can happen when a person undergoes a preventive screening or a general health examination (Svenaeus 2009, 62–63). Since many of the participants in this study find out about their disease in this way, I will discuss the implications of this scenario quite extensively in the next chapter.

At this point, I wish to address another important qualification that Svenaeus makes regarding the relationship of the five stages in his model. When a person goes through the process of falling ill, he writes, the stages do not replace each other. Rather, when a new stage is reached, it is added to the previous ones, an addition that does not leave the previous stages unaffected; instead they 'take on a new character through being supplanted by new ones in a kind of synthesis' (Svenaeus 2009, 63).

To sum up this section, I will recapitulate the main points that I bring with me from Toombs's and Svenaeus's models of falling ill described above. What I find fruitful first of all in these models is their emphasis on the fact that illness enters into the entire being-in-the-world of the embodied person. In beginning in a person's prereflective and practical engagement with the world, illness causes a temporary or prolonged disruption of the familiarity that ordinarily characterises the body–world relationship, bringing about a feeling of unhomelikeness (Svenaeus 1999). This understanding of illness enables me to study how pervasive cultural processes relate to and affect the way in which different stages of the process of falling ill are experienced and managed by the sick persons. This connects to the second main aspect that I bring with me, namely the intimate and complex relationship between illness and disease. The first three stages of Svenaeus's model clearly belong to the concept of illness, and the fifth and final stage to the concept of disease, while the fourth – 'disease pondering' – seems to be some kind of intermediate category, which has its roots in the pervasive presence of biomedical knowledge in the everyday lives of citizens of many of today's societies. The existence of this category clearly illustrates the intimate and complex relationship between illness and disease. But it is also evident in the synthetic character of the various stages in Toombs's and Svenaeus's models, through which the stages preceding the disease state are not left behind but are transformed once this stage is entered. What I finally find fruitful in the models presented above is their emphasis on the process of alienation and objectification that commences already in the initial stages of the process of falling ill. This emphasis enables me to study the interaction between the various forms of bodily alienation and objectification that emerge in the lives of persons afflicted with chronic diseases. Throughout this book, for example, I write extensively about the relationship and intense interplay between the ill body-as-object, which belongs to the first three stages in Svenaeus's model, and the diseased or medical body-as-object,[25] which belongs to the fifth stage in Svenaeus's model.

A phenomenological methodology

In this final section of the chapter, I describe how the phenomenological points of departure presented above have affected the way I view and analyse the empirical material I have gathered. It would be wrong to claim that this phenomenological approach constitutes a kind of pre-established methodological matrix that I simply filter the empirical material through

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[25] Since, in my use of the term, disease is inextricably intertwined with biomedicine, I use the terms 'diseased body-as-object' and 'medical body-as-object' synonymously throughout this thesis.

(cf. van Manen 2014, 29). Rather, these theoretical points of departure provide a form of ontology that enables me to grasp the nature of the material gathered. This ontology is made analytically operable, however, by means of a number of concepts, such as the lived body, the oriented body, dys-appearance, and disorientation. These concepts have provided me as a researcher with a particular orientation that has enabled me not just to analyse the empirical material, but to gather it in the first place. Throughout my work with this thesis, there has been a constant interplay between my empirical and theoretical explorations. For instance, I had just started my fieldwork in Riga when I began reading Sara Ahmed's *Queer Phenomenology* and realised that the way the patients were oriented during a haemodialysis session – in relation to the machine and to each other, for example – greatly affected their experiences, an insight which directed my researcher-body to take note of these orientations more thoroughly.

From the perspective of my phenomenological points of departure, then, what is the character of the empirical material I have gathered? According to phenomenologist Max van Manen, 'phenomenology is the project that tries to describe the prereflective meaning of the living now' (2014, 34). It aims to describe human experience as it is prereflectively lived in the present moment. In reality, however, this is a virtually impossible project, van Manen admits, since the now as we live it is inherently fleeting. 'The present moment of the now is always already absent when we try to capture or reflect on it,' he writes (van Manen 2014, 59). But it is not completely lost. As my theoretical discussions in the previous sections have suggested, as lived and oriented bodies we inhabit a here and now that is always completely infused with the past and the future. We constantly sediment past experiences into our corporeal schema, from which we orient ourselves towards future activities. But this process would not be possible if we did not inhabit a world, if we did not exist in an already materially, intersubjectively, and spatiotemporally oriented situation.

All of the interviews and observations I conducted during my fieldwork were situated in this sense. When I met a person with kidney failure for an interview, I met someone who described his or her experiences and views from the point of view of a particular embodied situation, a situation indissolubly intertwined with the world and with past and future events. As several phenomenologically inspired scholars have argued, narratives are told *through* the body of the narrator, through a corporeal schema carrying past experiences and future actions with it (see e.g. Frank 1995, 2; Hydén 2005; Bremer 2011, 50; Alftberg 2012, 38–41). This does not mean that we should not take into account the circumstances of the particular situation in which a story is told. It just means that the now in which a story is told is never completely external to the past and future events it describes. The same is true for the events and actions I witnessed during my observations. When, for instance, I watched a self-care haemodialysis patient with practiced hands connect him- or herself to the machine, the habitualness and speed with which the necessary actions were performed informed me about past repetitions and the future-oriented ambition to get the treatment started as soon as possible. To sum things up a little, even though stories are told and actions are performed in an embodied presence, they extend beyond this here and now into a particular worldly context, from a past and towards a future.

Like anthropologist Cheryl Mattingly (1998, 44), I see no opposition between narratives and actions. Rather, as Alftberg points out, they are different manifestations of the same bodily orientation, and both constitute ways of acting in the world (2012, 39). But they are also ways of experiencing the world. To the degree that we experience ourselves when we tell stories, we quickly identify the narrative quality of the events we experience. As phenomenology tells us, we perceive and experience the world through patterns of meaning rather than through our sensorimotor organs as primitive functions; our perceptions and experiences do not become an unsorted mass of impressions but combine to form part of that meaningful whole which is our being-in-the-world. Our actions are therefore to an equal extent permeated with and productive of meaning, as are our verbalised accounts. They are both simultaneously of and about our lives (cf. Mattingly 1998; Hydén 2005).

But just because they are intimately intertwined and manifest themselves through our oriented embodied existence, they should not be completely conflated. Verbal accounts are reflective thematisations of actions, views, and experiences, while most of our actions tend to be prereflective. Interestingly, this has led anthropologist Michael Jackson to conclude that participant observation is the superior method for grasping the prereflective meaning of the living now (see Alftberg 2012, 39), while van Manen views what he terms 'the phenomenological interview' as the best method (2014, 314). Instead of choosing sides in this debate, I have chosen to use both methods, taking account of their similarities as well as their differences throughout my work. Moreover, since the majority of the participants in this study, when they fell ill with kidney failure, experienced a disruption of their prereflective being-in-the-world and an emergence of their embodied existence into their reflective awareness, my research interest in this thesis is to a large extent oriented towards the process through which this prereflectiveness is rebuilt, that is, towards the constant interplay between and mutual dependence of the prereflective and the reflective levels and the way this interplay is situated in a normatively charged cultural context. As a consequence, in performing a cultural analytical phenomenological project, my objectives differ to some extent from the objective of phenomenology as it is formulated by van Manen. Rather than focusing solely on 'the prereflective meaning of the living now', I am interested in the dynamism of human embodiment as it manifests itself in the interplay between the prereflective and reflective levels of consciousness and as it is expressed both in actions and in verbal accounts.

Finally, I want to remark that I view the empirical material on which this study is based as the result of relational exchanges between the participants and me. It is the result of certain kinds of interaction and communication that occur in particular social situations, circumstances that affect the form and content of the material (Fägerborg 2011). Ethnographic fieldwork constitutes meetings between two, or more, persons whose situatedness and orientation in the world make the telling of some stories and the performance of some actions more possible than others. The empirical material that results is therefore inextricably intertwined with the relational and societal situation in which it is produced (Bremer 2011, 50; Alftberg 2012, 40). However, as my above discussion has revealed, it also extends far beyond this particular situation.

3. Encountering kidney failure, renal replacement therapies, and oneself as a patient

In this chapter I analyse and explore the participants' way towards patienthood. First I direct my interest towards what transpires before renal replacement therapies – haemodialysis and transplantation – are initiated. I conduct a thorough analysis of the participants' experiences of falling ill and being diagnosed with kidney failure. In this analysis I highlight the significance of the way in which the disease and illness enters into the participants' lives for how they subsequently experience and cope with their dependence on renal replacement therapies in general and haemodialysis in particular. I then go on to explore the participants' first encounters with renal replacement therapies, paying particular attention to the moral and normative charge of these encounters.

The complexities of falling ill with kidney failure

I begin by delving deep into the complexities of the relationship between health, illness, and disease. In the participants' accounts of falling ill and being diagnosed with kidney failure, this complexity emerges with great intensity. Ambiguities persist despite the biomedical ambition to understand, delimit, and name bodily dysfunctions and ailments by means of diagnoses. These are ambiguities that persons who fall ill with kidney failure often have to work hard to come to terms with.

Illness first, then disease

When Ivan fell ill with kidney failure he was only nineteen years old. At the time, he was working in construction and still lived with his parents. To a certain degree he sees himself as responsible for the outbreak of the illness. He had fallen ill with tonsillitis and had not treated it properly. Instead of resting he worked and hung out with friends. But he also blames his family doctor. She did not take the symptoms that subsequently emerged seriously. When he went to see her for the fourth time, with back pains, she dismissed it as a case of lumbago. But 'it seemed like I was beginning to fall ill,' he tells me. And on 10 September 2007 he saw the oedema for the first time.

> My face was swollen and I thought I hadn't slept enough. I thought it wasn't anything. It looked like water had accumulated. I thought it would recede. And the water did recede. Then my abdomen slowly started to show, and my entire body began to swell. And around October 20th of 2007 I felt, my mother told me, that it was getting worse. Even so, I had celebrated my birthday. And then it started… My temperature rose. I thought I'd eaten something because I had been vomiting. And, in addition, I was having problems with stool. I had visited the family doctor, but she didn't tell me anything, just 'You are healthy!' So I lay at home treating myself with the medicine I had at home. But it turned into [a situation where] I couldn't do anything anymore. My legs looked like paws because I was so swollen.

At that point, Ivan says, 'I had swollen up so much that we didn't know what to do.' But they did not call an ambulance. If they had, he tells me, he would have been taken to either one of two hospitals in Riga that he had heard negative judgements about. Instead, his brother picked him up and drove him to the hospital where, at the time of our interview, he receives haemodialysis. 'But the doctors didn't want to admit me,' Ivan says. Apparently they did not have room for him. Eventually, though, a doctor took notice of him. 'He poked my leg with his finger, and it got stuck there. And he told me to "do analysis immediately!"' Later the same day Ivan was referred to the department of nephrology, where a biopsy was performed, which revealed that his problems were related to his kidneys. At this point the medical personnel wanted him to undergo haemodialysis. But Ivan refused. Instead, he was prescribed medications. During the spring of 2008, however, his condition deteriorated dramatically and haemodialysis had to be initiated urgently, without his consent. At this point, he was so ill that he felt indifferent, he tells me. He felt that he was close to death and did not care what happened to him. His doctor later told him that his lungs had been about to burst from all the water that had accumulated in his body. This oedema has permanently marked his body. The skin on his arms is floppy and full of stretch marks.

In many ways, Ivan's story of falling ill follows a conventional chronology. First he experienced illness symptoms. Then he went to see a doctor who established the illness as a disease. For Ivan, though, the second step was not so easily achieved since his family doctor failed to diagnose him correctly. But when the illness reached an unmanageable state and his brother took him to the hospital for emergency treatment, he finally found himself in the hands of a doctor who understood the immediate necessity of determining the underlying biological dysfunction. Thus, even though it took some time, Ivan's illness was eventually provided with a diagnosis and established as a particular disease. This is the order of events that most of us have in mind when we think of the process of falling ill; our visit to the doctor is preceded by our experiencing illness. This is also the order of events that characterises the phenomenological conceptualisations of the process of falling ill that I described in the previous chapter. As we saw, Toombs (1992) and Svenaeus (2009) divide this process into five stages: 'pre-reflective experience of discomfort', 'lived, bodily discomfort', 'suffered illness', 'disease pondering', and 'disease state'. In what follows, I employ this theoretical model in my analyses of the participants' stories of falling ill.

Ivan's account does not reveal much about the first stage in the model: 'pre-reflective experience of discomfort'. But it is likely that the tonsillitis he regards as the cause of his illness was preceded by some sort of general discomfort that interfered with the activities that he wanted or needed to engage in. The paucity of information in Ivan's story about this may be explained by the character of the illness at this stage in the process of falling ill. At this stage, the illness is only experienced prereflectively as an indistinct interference with particular activities or as an elusive change in the surrounding world. It therefore lies in the nature of illness at this stage to escape verbal articulation.

Ivan's story, however, is fraught with 'lived, bodily discomfort', which is the second stage in the model. Here, the body begins to dys-appear for the person who is falling ill. But as Svenaeus points out, illness at this stage is still to a certain degree prereflective, since it precedes the person's thematisation of the body as ill, in the form of 'distinct thoughts and hypotheses' (2009, 62). Before his emergency trip to the hospital with his brother – over the course of about one month – Ivan experienced lived, bodily discomfort in the form of back pain, swelling, nausea, and fever, experiences that quite quickly brought him to the next stage in the process of falling ill: 'suffered illness'. On several occasions, Ivan clearly experienced this lived, bodily discomfort as so 'unusual, prolonged [and] uncomfortable' that he came to the conclusion that it formed 'part of a large whole', which, according to Toombs, constitutes the main characteristic of suffered illness (1992, 33–35). At first, he was able to shrug off his swollen face as caused by a lack of sleep. But when his abdomen began to swell and he developed a fever, experiencing severe nausea, it was clear to him that these bodily dys-appearances formed parts of a larger whole. At this point, Ivan began to engage in 'disease pondering', the fourth stage in the process of falling ill, interpreting the swelling, fever, and gastric problems as symptoms of food poisoning. When he went to see his family doctor, however, he was told that he was healthy.

During the month-long period preceding Ivan's emergency trip to the hospital, he went through several stages of the process of falling ill several times. Since he did not receive sufficient medical attention and explanation for either his back pain or his swelling and nausea, he was forced to return home and try to live as if he were well. But the 'existential demand' of the dys-appearances that kept returning was so forceful that this eventually became impossible (Leder 1990a, 92). Ivan is not alone among the participants in this study in having had this experience. Carlos, for instance, went to an emergency unit in Stockholm four times before the severity of his condition was recognised. It was not until he brought a list of tests that needed to be made, compiled by a friend of his, that he was finally admitted to the hospital and provided with an explanation for his suffering. Eventually, so too was Ivan. At the emergency unit, a doctor finally took notice of the severity of his condition and, after being referred to the nephrology department, Ivan was diagnosed with kidney failure, thereby reaching the 'disease state', which constitutes the final stage in Svenaeus's and Toombs's models.

At the time of our conversation, Ivan has gone through all five stages of the process of falling ill. In addition, he has become quite an experienced haemodialysis patient, having undergone the treatment several times a week for almost two years. It is from this perspective that he tells me about his experience of falling ill with kidney failure. This is an embodied perspective, as Svenaeus points out, that incorporates, in a synthesised form, all five of the stages of the process of falling ill (2009, 63). This is apparent, for example, when in our conversation Ivan says, 'It was on September 10th, 2007, that I saw the oedema for the first time,' referring to his first noticing that his face was swollen. At the time, Ivan most likely did not conceive of or refer to his swollen face as oedema. As he tells me, he thought it was due to too little sleep. His use of the medical term oedema is almost certainly the result of the form of synthesis that Svenaeus writes about, a synthesis accomplished not only by means of his passing through the five stages of the process of falling ill but also by means of the time that has passed since he was diagnosed, during which he has lived with the illness and undergone haemodialysis. For Ivan, the kind of swelling he experienced when he fell ill now *is* oedema, and when he suffers similar bouts of swelling these days, as haemodialysis patients not infrequently do, the concept of oedema quite likely affects his experience of it, all the way down to the first stage in Svenaeus's and Toombs's models. In what follows, I will delve deeper into the complex relationship and interplay between health, illness, and disease that is evident in Ivan's story by relating it to and describing other persons' experiences of falling ill with kidney failure.

Illness following disease

When Marianne was thirty-one she was diagnosed with glomerulonephritis.[26] She was pregnant with her daughter at the time, and it was during a regular check-up at the maternity ward that they noticed that something was wrong. Marianne was told that it was related to the kidneys and was referred to the nephrology department, where a biopsy was performed. The result of the biopsy and the associated diagnosis were communicated to her during a consultation with a doctor, who after giving her the information asked her how she felt, to which she replied, 'Well, thank you, I feel good.' When recounting this episode during the interview, Marianne says,

> And then I went home and talked to my husband, and I said to him, 'It's probably nothing to worry about,' thus totally repressing it. But I have understood that this is not uncommon. Many people do it. Then they came in small portions, these anxiety attacks, where I felt that maybe I would die. It just surfaced during the summer.

It was spring when Marianne found out about her glomerulonephritis, but it was not until summer that the meaning of this really dawned on her and began to manifest itself in the form of anxiety attacks. Other than this, though, Marianne felt well. She did not experience any physical discomfort, a fact that encouraged her to question the truthfulness of the diagnosis. 'They've of course mixed up the samples,' she thought, 'because I don't feel anything.' Contributing to this theory was the fact that the baby girl she gave birth to later that year weighed almost four kilos. She had heard that people with kidney problems tend to have babies that are smaller than normal, and when her daughter was not, she interpreted this as a confirmation of her theory that she had been misdiagnosed. However, when she began going for regular check-ups after her child was born and her doctors told her that kidney failure and dialysis were 'far off in the distant future', something that would happen in twenty years or so, she began to come to

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[26] The diagnostic term glomerulonephritis denotes a set of conditions that cause inflammation of the kidneys, impairing their filtering capacity (Chalmers 2014).

terms with her diagnosis. 'These were the expectations that the doctors gave me,' she says. But as it turned out, Marianne had been misdiagnosed: she had not glomerulonephritis, but vasculitis.[27] And, in the end, it took her kidneys not twenty years to fail, but less than two.

This course of events was something no one had expected. Since she went for regular check-ups, the doctors and Marianne herself thought that the disease was under control. But because they monitored the wrong disease, they missed the progression of the one Marianne was actually suffering from, and which, two years after she received her initial diagnosis, began to progress rapidly. One day she was in such a bad state that she had to make an emergency trip to the hospital. She had severe cramps, 'which is a very late stage of uraemia',[28] she tells me. At the hospital, haemodialysis had to be initiated immediately.

Marianne's experience of falling ill with kidney failure began at the fifth stage in the theoretical model of falling ill described above and in the previous chapter. Unlike Ivan, Marianne was diagnosed before she experienced any illness symptoms. Their diagnoses entered their respective lives in radically different ways and had radically different consequences for them. This attests to the ambiguous nature of biomedical diagnoses. From a medical and bureaucratic perspective, diagnoses exist to bring order, to explain, classify, and delimit bodily dysfunctions in order that they can be understood and, ideally, treated and cured (Forss et al. 2004, 319; Sachs 2004, 59; Drakos and Hydén 2011, 17). From the perspective of persons embodying the diagnosed bodily dysfunctions, matters are often more complicated. Diagnoses do not just enter people's lives as neutral pieces of information about the state of their body. Rather, they have complex, contextual, and situational consequences that the diagnosed persons actively have to make sense of, manage, and try to incorporate into their embodied being-in-the-world, a fact that will become increasingly evident as this thesis progresses (cf. Forss et al. 2004; Hagen 2013b).

Thus, receiving a diagnosis can be experienced as both a positive and

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[27] Vasculitis is a vascular disease ordinarily affecting not only the sick person's kidneys but also his or her skin, joints, lungs, eyes, and nervous system (Pattison 2004, 60).

[28] Uraemia denotes the clinical syndromes that appear in the last two stages of chronic kidney disease (Attman and Alvestrand 2004, 198).

negative event, but seldom as a neutral one. On the positive side, diagnoses first of all provide suffering with a name, a denomination that may afford meaning and context to the suffering (Sachs 2004; 60; Svenaeus 2013, 21). This is closely related to the descriptive and explanatory function of diagnoses. According to Drakos and Hydén, diagnoses have a dialogical character; they are often the result of a meeting between a patient and a doctor who tries to understand the patient's ailments and attempts to describe and explain them in medical terms. Further, diagnoses tend to be future-oriented; they often include predictions – ordinarily expressed in statistical probabilities – in the form of a prognosis, that is, an expected progression of the disease (Drakos and Hydén 2011, 23–24). If the dialogical encounter in which the diagnosis is enacted is carefully performed, Sachs argues, it can even function as a form of treatment in itself (2004, 58). Moreover, diagnoses can help families understand and cope with a family member's illness; provide ground for a beneficial collectivisation in the form of various support groups and associations; offer a means whereby the sick person can legitimise his or her suffering; and provide access to health care, social security, and various other forms of assistance (Sachs 2004, 58; Drakos and Hydén 2011).

There are also several negative sides to diagnoses, which ordinarily coexist with the positive. It cannot be stressed enough that whether a diagnosis is perceived as primarily positive or primarily negative depends on the particular situation and context of the diagnosed person, situations and contexts that are variable. The positive effects recounted above may therefore not be experienced at all as such, and almost all of them have a negative flip side. The most obvious example of this is the way a diagnosis, by determining the nature of the suffering, brings about the end of a period of both difficult and hopeful uncertainty and informs the sick person that a bodily change has occurred which may alter life forever, or end it altogether. Diagnoses narrow the ways in which suffering may be understood and force sick persons to orient their lives in new, sometimes radically new, directions. Further, diagnoses may be severely stigmatising. In attaching a particular bodily or mental dysfunction to a person's existence, categorising him or her as belonging to a certain group of sufferers and signalling that he or she is dependent not only on health care but also on various forms of societal assistance, diagnoses may cause social marginalisation of the diagnosed person (Kierans 2005; Hansson 2007; Drakos and Hydén 2011; Svenaeus 2013).

Ivan's story clearly illustrates the ambiguity of diagnoses and the complex relationship between health, illness, and disease. When his family doctor could not find a disease she told him that he was healthy, even though he experienced himself as ill. But when he finally did receive a diagnosis, this denomination and explanation was not sufficient to convince him that he needed to undergo haemodialysis, so he refused to do so. Ivan did not see the intimate connection between diagnosis and treatment, a link that was most certainly self-evident to the doctors. Such ambiguities are apparent also in the way Ivan has experienced and managed living with the diagnosis since he began to undergo haemodialysis. On the one hand, he says, he is 'grateful to the illness' since it has made him more empathic. Before he fell ill, he tells me, he did not 'spend [his] time very well'. He was a skinhead, supporting the right-wing movement, and he says that if it were not for the disease he would probably be in prison. But due to the disease, he has developed a 'different attitude towards people'. On the other hand, Ivan and his family are not fully convinced that the biomedical explanation for his suffering is the correct one. When he had just started haemodialysis, his brother brought a 'wise woman' from Estonia to see him, who told him that his illness was caused by the evil eye. Ivan is convinced that this woman can cure him. The problem is that she lives in Estonia. But he is planning to go there the summer following our interview.

On the one hand, then, Ivan sees the entry of the disease and the treatment into his life as a gift, as something that has forced him to orient himself away from his previous, destructive lifestyle. On the other hand, he is not fully convinced of the accuracy of the diagnosis and the effectiveness of the treatment that he is undergoing. At least, he hopes, alternative routes towards a cure might exist.

Marianne's story likewise attests to the ambiguity of diagnoses. For her, the ambiguity consists primarily in the fact that she was diagnosed before she experienced illness. She was told that she was sick when she felt completely healthy, which initially encouraged her to doubt the accuracy of the diagnosis and later on gave rise to anxiety attacks. In recent years, a growing number of people have found themselves in similar situations. Medicine has namely become increasingly capable of predicting the onset of illness in advance – by diagnosing the bodily dysfunction before it emerges as symptoms of illness (Sachs 2004), by identifying bodily changes that may cause disease (Forss et al. 2004), or through a genetic screening that predicts the future onset of disease or identifies a particular genetic makeup that puts a person at 'genetic risk' of eventually developing a disease (Rose 2007; Hagen 2013b). As the research on these new predictive capabilities of medicine has shown, patients who are revealed to be 'asymptomatically ill'[29] (Rose 2007, 111) often experience themselves as having been thrown into a state of uncertainty, into an ambiguous situation where they find themselves in between the categories of health, illness, and disease (see e.g. Forss et al. 2004; Hagen 2013b).

For Marianne, being diagnosed before she fell ill was disorienting. One could even claim that she fell ill as a consequence of finding out that she had a disease. This possibility has been pointed out by Svenaeus (1999) and Sachs (2004), among others. In such instances, the illness experienced by the person receiving the diagnosis most often does not correlate with the symptoms that medicine attaches to the particular diagnosed disease state. Rather than experiencing headaches, nausea, and fatigue, which are common symptoms of kidney failure (see Kierans 2005), Marianne suffered from anxiety attacks. If we understand illness as an unhomelike being-in-the-world, as I do here, the anxiety attacks Marianne experienced can be seen as illness since they were the result of a sudden and radical change in the structure of her being-in-the-world (Svenaeus 1999, 177). As a thirty-one-year-old expectant mother, Marianne was not oriented towards a future in which she would be sick and dependent on medical care. She was

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[29] From a phenomenological point of view the notion of asymptomatic illness is to some extent oxymoronic, since illness denotes a person's experience of an unhomelike being-in-the-world. The more phenomenologically consistent term would be 'asymptomatically diseased', since what has been established is that the person is at risk for or already embodies a disease state that will eventually cause symptoms. However, I retain the term 'asymptomatically ill' because it signals the ambiguousness of the situation into which the person who has received a diagnosis or undergone a predictive screening have been thrown.

oriented towards a life characterised by her taking care of and raising a small child together with her husband, an orientation that the diagnosis put radically into question. Not unexpectedly, this disoriented Marianne, causing her to experience her being-in-the-world as unhomelike, an illness state for which she received no medical attention.

Seen from the perspective of Svenaeus's and Toombs's models of falling ill, the diagnosis also caused Marianne's body, or at least one of its organs, to quite rapidly and radically emerge, or dys-appear, as alien, an alienation that was reinforced by the absence of any prior experiences of illness. From one day to the next Marianne found out that she embodied an 'alien inside' which would affect her life profoundly in a not too distant future (Åkesson 1999). As Svenaeus (2009) and Leder (1990a) point out, when the body presents itself to consciousness as alien it is also always experienced as an object. But just as there are several causes for and forms of bodily alienation, there are several causes for and forms of bodily objectification. For Ivan, the objectification caused by the diagnosis primarily functioned as a means whereby the objectification caused by illness received an explanation and could be alleviated, at least initially. In Marianne's case, the diagnosis did not have this explanatory and alleviatory function. For her, there was no suffering to relieve or explain. Consequently, the alienating and objectifying effect of the diagnosis was greater – at least in the short term – and disoriented her drastically.

In Ahmed's view, disorientation is intimately linked to objectification. She even writes that, 'in simple terms, disorientation involves becoming an object' (Ahmed 2006, 159). It is by thematising and bouncing against some bodies as objects, Ahmed argues, that the world becomes spatiotemporally oriented in line with dominant bodily orientations, such as, for example, whiteness and heterosexuality. As a consequence, a world is produced which permits the involvement and extension of some bodies more than others, a world in which these 'others', to a greater extent, experience difficulties in finding their way, in orienting themselves. Processes of bodily objectification are thus an inherent feature of the repetitive acts by means of which the world acquires direction. This does not mean that the scope of action of those who become disoriented and objectified is completely eliminated. Rather, Ahmed writes, what should be asked is 'what we do with such moments of disorientation, as well as what such moments can do – whether they can offer us the hope of new directions, and whether new directions are reason enough for hope' (2006, 158). Since disorientation and objectification are so intimately entwined, we should ask the same questions regarding moments of bodily objectification – as I do throughout this book.

As the social scientific and humanistic research on the new predictive capabilities of biomedicine has shown, the state of uncertainty and disorientation into which people are thrown after they become diagnosed as asymptomatically ill gives rise to a vast array of actions among these persons through which they endeavour to reorient themselves. These can be anything from attempts to make sense of the identified '"alien inside" by invoking various perceivable aspects within [one's] everyday life' (Hagen 2013b, 59), to efforts at taking control over one's care process by seeking advice from multiple expert sources or gathering as much information as possible about the condition (Rose 2007, 111). In Rose's view, activities such as these attest to the extent to which contemporary biomedicine participates in the neoliberal autonomisation and responsibilisation of the individual. By informing asymptomatic persons of their embodiment of a serious disease without offering them any comprehensive instructions on how to cope with and act on this disease, biomedicine creates a situation in which prospective patients are made responsible for finding their own way of dealing with being asymptomatically ill (2007, 111).

Marianne initially used perceivable aspects of her everyday life to suspect that she had been misdiagnosed. These aspects spoke an unequivocal language. Not only did she feel completely healthy, but she also gave birth to a normal-sized baby. The suspicion of misdiagnosis that these aspects gave rise to, however, did little to help her overcome the state of uncertainty into which the diagnosis had thrown her. Instead, a process of reorientation began when she abandoned her doubt as a result of the prognosis that was communicated to her when she started undergoing recurrent check-ups. By means of this prognosis, which said that the real outbreak of the disease was twenty years in the future, Marianne not only began to find a way to orient herself again, but also initiated the process of attempting to incorporate the diseased body-as-object into her corporeal schema. I will return to the latter process in the next chapter. Here, I want to focus on the quite paradoxical fact that the very diagnosis that disoriented Marianne itself contained the seed to her reorientation.

This is a paradox that may be untangled if one views diagnoses as lines, in Ahmed's sense of the term. By means of their future-orientedness – which they gain primarily through comprising a prognosis – diagnoses accumulate into lines possible, or impossible not, to follow. As such, they promise a certain 'return'; as followers of a line we can expect that '"this" or "that" will follow' (Ahmed 2006, 17). This is an inherent feature of lines, Ahmed argues. But the realisation of this return requires our active commitment to the line; it requires that we make the 'social investment' necessary for its persistence (Ahmed 2006, 17). In Marianne's case, this investment consisted in going for regular check-ups and participating in the preventative measures recommended by the doctors, what is generally referred to in the medical sphere as 'compliance' (May and Mead 1999; Sharp 2006, 122). In doing so, she could expect the entry of dialysis into her life to be far off in the future. Marianne's alignment with this line was thus 'not disinterested: to follow a line takes time, energy, and resources', as Ahmed contends (2006, 17).

For Marianne, the process of aligning herself with her diagnostic line was a deeply transformative event, one that made her feel homeless in the world for a period and required her to reorient her life to expect the outbreak of a chronic disease and dependence on invasive medical treatments later in her life. It is clear that she did not have much choice but to accomplish this alignment. She could have refused to participate in the medical check-ups and preventative measures, but it is apparent that the diagnostic event itself had already disoriented her in such a way that she needed the assistance and predictive capabilities of medicine.

The asymmetry that characterises the doctor-patient relationship – in which the medical knowledge possessed by the doctor takes precedence over the patient's experiential knowledge – also likely limited Marianne's scope of action (Svenaeus 1999, 243; Drakos 2012, 186). Medical diagnoses are generally considerably compelling. To use the Althusserian terminology utilised by Ahmed (2006, 133–134), one can say that diagnoses 'hail' or 'interpellate' persons; they compel persons to 'turn', to change direction, as a result of their address. By naming and predicting the development of a dysfunction in the body, diagnoses redirect us. They force us to alter our corporeal schema so that it aligns itself with the diagnostic line outlined for us – at least this is so in the case of chronic diseases. What Marianne first experienced as a disorienting paradox – 'I have a disease but I feel completely healthy' – was later resolved when she began to find ways of orienting herself in the direction of the prognosis. The simultaneously disorienting and reorienting nature of diagnoses, evident in Marianne's story, is thus not paradoxical if the sick person is able to align him- or herself with its direction. What this tells us is that there is ample reason to nuance Rose's statement above about the autonomisation and responsibilisation of contemporary predictive medicine. On some occasions, even though the person is asymptomatically ill, the diagnosis and prognosis are powerful enough to accumulate into a line that is possible to follow. However, following this line may itself entail taking increased responsibility for one's body.

Marianne's diagnosis unfortunately turned out to be inaccurate, and so too her prognosis. She fell acutely ill after just two years and had to start haemodialysis on an emergency basis, thus having to drastically and instantly reorient her life once again. Someone who both succeeded in orienting himself in line with the diagnostic line and received the promised return in the form of a correct prognosis was Rune. I turn to his story below.

Receiving the promised return

When Rune was diagnosed with glomerulonephritis he was thirty-five years old and at the peak of his career in the pulp and paper industry, a line of work that entailed a lot of travel. It was after returning home from one such trip that Rune's body dys-appeared in a way that motivated him to go see a doctor. This is how he describes it:

> I was away on a two-week long trip […] and it was cold. It was during the fall and I was supposed to go into their [the company he visited] warehouse and look at some things, and it was cold, and I had a cold already

> when I left […]. At that time I played tennis every weekend and I had missed one practice, and I was supposed to return home the following weekend and wanted to play. This triggered something so that when I peed afterwards I peed almost black: dark, dark, dark. And then, my wife, I asked her to have a look at it, she used to be a nurse. She said, 'You should go to the hospital and ask them to have a look at that.'

At the hospital he got to see a nephrologist who said, '"This is what we call glomerulonephritis, and it can take ten years before the kidneys are finished."' 'But he made it clear to me that it only goes one way, that it had entered a chronic stage. So it wasn't anything acute. And, in fact, it probably took eight to nine years, I believe, until I had to start dialysis,' Rune says. During these eight to nine years he never experienced any symptoms of the disease. When I ask him if he felt sick before starting dialysis he says, 'No […] I can't say that I did, not that I can remember, anyway. Maybe I was a little bit more tired, because, of course, my test results showed that it was necessary to start dialysis. And the longer you wait the worse you feel…'

Unlike Marianne, Rune experienced illness before he received a diagnosis. First he suffered illness in the form of a cold whose symptoms he recognised well and did not interpret as serious (cf. Sachs 2004, 58); the illness went through the first four steps of Svenaeus's model without reaching the fifth. Even though it quite likely affected the activities he engaged in, he saw no reason to cancel them. When he returned from his business trip, having missed a tennis practice, he was eager to play and, ignoring his suffered illness, went. This sparked the dys-appearance of his body in a way he did not recognise, and which he experienced as something more serious than a common cold, as forming 'part of a large whole', an illness, which he did not know anything about (Toombs 1992, 35). Fortunately, he could consult his wife, who had a medical background, with whom he disease pondered and decided that it would be wise to see a doctor. At the hospital, he was quickly referred to a nephrologist who diagnosed him with glomerulonephritis and estimated kidney failure and dialysis to be a decade away, a prognosis that turned out to be correct.

In my conversation with Rune it is evident that the temporal gap that opened up at the time of the diagnosis – between the diagnosis and the onset of the disease – helped Rune to manage receiving the diagnostic information. Even though he probably did not expect to be diagnosed with a chronic disease when he went to the doctor, I get the impression that he quite quickly aligned himself with the future-oriented diagnostic line and that he therefore did not expect the disease to impact his life before a decade had passed. This can be illustrated with the answer Rune gives when I ask him to describe how he felt when the doctor told him about the diagnosis. He says, 'Well, I had time then to get used to the thought of this during these years, so to speak, and I knew what was coming…'

In this reply, Rune's focus is not, even though I ask him specifically about it, on the diagnostic event. Rather, his focus is on the onset of the disease and the initiation of haemodialysis. The time, he says, that separated receiving the diagnosis from the onset of the disease enabled him to get used to the thought of living with a chronic disease and undergoing invasive medical treatments. One could interpret this answer as the product of a misunderstanding: Rune simply misinterprets my question as concerning the initiation of haemodialysis rather than the diagnostic event. But I do not think this is the case. What I believe Rune is trying to put across is that the temporal gap between diagnosis and disease that opened up when he was diagnosed fundamentally affected the way he experienced receiving this information. It helped him tone down the severity of it and gradually get accustomed to what it would mean for him. Remember that he was working hard at the time, enjoying the progress of his career in the pulp and paper industry, a line of work that he liked very much. During this period, Rune and his wife also adopted two baby girls, which naturally constituted major events in both their lives. Thus, Rune had every reason not to let the diagnosis impact the orientation that his life was taking, and the temporal gap that opened up and the diagnostic line that consequently materialised allowed him to do so.

However, time would not have been an asset if Rune's body had not remained absent. Aside from peeing black once, Rune did not experience any symptoms of illness. During the eight to nine years that separated the diagnosis from the onset of the disease, Rune did not fall ill or experience any unusual or prolonged dys-appearances of his body. During all this time he was able to forget about his body for extended periods. He did go for regular check-ups, but these, it seems, as was the case with Marianne, only reinforced the sensibleness of aligning himself with the future-oriented diagnostic line. It is likely that these check-ups and the preventative and preparatory measures taken as the onset of the disease came closer also played a major role in enabling Rune to get used to the thought of starting haemodialysis. Through them he was gradually introduced to the milieu, knowledge, and practice that he was going to be forced to integrate into his life at a later stage.

What happened during the years that separated the diagnosis and the onset of the disease was that Rune's alignment with the diagnostic line gradually affected the orientation of his entire life. Although he could remain aligned with the lines he was following prior to the diagnosis, these lines had to be gradually redirected to promise a different return. They no longer promised a return in the form of a long and healthy life with his wife and daughters, but in the form of a decade of living as usual, followed by a radical transformation. But the long duration, and therefore slow pace, of this redirection enabled Rune to remain oriented and gradually incorporate the diseased body-as-object into his corporeal schema, thereby avoiding disorientation. Thus, the temporality of the diagnostic line helped him manage the ambiguous situation into which he was thrown when he received the diagnostic information. As we shall see in the next sections of this chapter, though, while a form of realignment of illness and disease takes place when renal replacement therapies are initiated, the radical redirection of life that this entails not infrequently causes disorientation itself.

It is important to keep in mind here that the embodied here and now that Rune – and all the other persons with kidney failure whom I interviewed – inhabits at the time of our conversation quite likely affects how he remembers and experiences the diagnostic event. The point of view that he embodies when we speak – when almost forty years have passed since he was diagnosed, and when he has undergone two transplantations and spent approximately a decade on haemodialysis – differs quite radically from that which he embodied when he received the diagnostic information. This might cause him to remember the diagnostic event as less dramatic than he experienced it to be at the time. But this way of recounting the event could also be the result of a narrative strategy on Rune's part. In toning down the impact that receiving the diagnosis might have had, in 'de-exceptionalizing' it (Amelang et al. 2011), he implicitly tells me that being sick with kidney failure is not such a big deal. Rather than completely diminishing the importance of his alignment with the future-oriented diagnostic line for his reaction to the diagnosis, though, these two qualifications merely nuance it. In receiving a beneficial prognosis, Rune experienced the materialisation of a line that was possible to follow, a line that, he realised, would allow him to retain the direction that his life had been taking, at least for a decade.

When information is scarce

What happens, then, if the nature and seriousness of the disease are not mentioned at all, if the information given at the time of the diagnosis is not sufficient to produce a diagnostic line that is possible to follow? This was the case for Yevgeniy. Throughout his childhood Yevgeniy had a hard time passing urine tests, and since he was going in for sports he was tested regularly. But it was not until 1983, when he was thirty years old, that the doctors were able to diagnose the condition. He had glomerulonephritis. But 'they said nothing,' he says. He was only told that there was no treatment and that he should drink herbal teas. Without receiving any further information about the nature of glomerulonephritis Yevgeniy left the hospital, and it was not until twenty-one years later, in 2004, that he experienced the first symptoms. During these twenty-one years 'I felt absolutely healthy,' Yevgeniy says. But in 2004 a severe thirst arose. He would wake five times a night having to drink a glass of water. According to the results of his own disease ponderings it could be a symptom of diabetes. So he went to the doctor, where blood tests were taken and it was revealed that his kidneys had failed. 'At once all of them panicked and said, "You should be dead!" and immediately referred me to another hospital,' where haemodialysis was immediately initiated.

During the twenty-one years that separated the diagnosis and the onset of the disease Yevgeniy was asymptomatic and did not worry about the disease. He says:

> If the doctors suggest that you drink herbal teas… If they had prescribed some pills, I don't know; if they had said that there was a threat of kidney failure [maybe then I would have been worried]. But they just told me to drink herbal teas, and that's all. […] So if they suggest that you drink herbal teas, how serious can the situation be?

Like Marianne and Rune, Yevgeniy was diagnosed before he fell ill. But unlike them, the information he received was sufficient neither to throw him into a state of uncertainty nor to produce a diagnostic line for him to follow. He was only told that there was no treatment for his condition and that he should drink herbal teas, which prompted him to forget about the disease and orient his life along the lines he was already following. If we take a closer look at what he was actually told, however, it is evident that although his interpretation was the most obvious, he could have drawn other conclusions. During the diagnostic event, Yevgeniy was told three things: that he was diseased, that there was no treatment, and that he should drink herbal teas. It was the third piece of information, and to some extent the second, that Yevgeniy took to heart, encouraging him to regard the disease as harmless. If instead he had put the emphasis on a combination of the first and second pieces of information – that he was diseased and that there was no treatment – he would likely have reacted differently. Thus there was a scope of action, albeit narrow, available to him. In the second scenario, he might have made more inquiries into the nature of the disease, or simply worried about it, felt disoriented (cf. Forss et al. 2004).

But one should remember that Yevgeniy was diagnosed in 1983, which was at the end of the Soviet occupation of Latvia, during which the asymmetry characterising the doctor-patient relationship was substantial (see Putnina 1999; McKewitt, Luse, and Wolfe 2002; Luse and Kapina 2011). It might therefore have been difficult, or even impossible, for Yevgeniy to make further inquiries into the nature of his disease. Wanting to get on with his family life – he had two small children at the time – and career – he worked as a police officer, embracing the second and third pieces of information must have seemed the most reasonable thing to do, since they allowed Yevgeniy to retain his alignment with the lines he was already following.

The asymmetrical doctor-patient relationship may also to a certain extent explain the sheer scarcity of information. When the medical system, not the patient, is responsible for the disease, as Kilkuts argues was the case in Latvia during the Soviet occupation, there is little point in informing the patient about it (Larsen and Kilkuts 2005, 55). But another explanation is also plausible. In the 1980s, medical resources were insufficient in the Soviet Union. There was, for example, an acute lack of pharmaceuticals (see Field 1995, 2002). As a result, Yevgeniy's doctors might have withheld the information from him simply because they lacked the means to affect the outcome of the disease, to effectively postpone its onset, for instance. Since they could not do anything about it they might have thought it better not to make Yevgeniy worried by informing him. In the end, then, one could contend that Yevgeniy fell ill according to a conventional chronology. Since he had almost forgotten about the diagnosis he had received twenty-one years earlier, he did not link the symptoms of illness that he began to experience in 2004 to glomerulonephritis, but began after a while to disease ponder and came to the conclusion that it could be diabetes, only to learn when he went to the doctor that he was in acute need of renal replacement therapies.

In this section I have analysed thoroughly some of the participants' accounts of falling ill and being diagnosed with kidney failure. These analyses have attested to the complex contextual and situational circumstances influencing how a person interprets and reacts to falling ill and being diagnosed with a chronic disease. As we have seen, this complexity is the result not just of the particular circumstances of a person's life, nor the often diffuse symptoms of illness, but also of the structure and practice of biomedicine itself, which either succeeds in creating a diagnostic line possible for the prospective patient to follow or throws him or her into a state of uncertainty.

Encountering the two treatment alternatives

In this section I turn to the participants' first encounter with renal replacement therapies. Since the vast majority of them meet dialysis before they undergo transplantation for the first time,[30] I begin with the former and relate the participants' descriptions of their first encounter with this form of treatment to the medical professionals' notions of the ideal way of doing so. I then go on to describe and analyse not so much the participant's first encounter with the transplant procedure itself, but rather the way in which this encounter tends to give rise to a shift in their orientation towards it. My focus here is therefore primarily on the thoughts and feelings that the participants have about transplantation before they undergo the procedure for the first time. I then return, in chapter 7, with an analysis of the way in which and the reasons why their orientation towards it shifts after they have undergone it.

Encountering haemodialysis

According to Dr Liepa, nephrologist at the unit in Riga, there are two ways in which a patient can encounter dialysis for the first time, a wrong way and a right way. 'The wrong way is if a patient comes here as an emergency case,' she says. In that case, a 'long time is needed for the patient to recover and, let's say, get well and start working or something. But if we see such patients – and, unfortunately, we mostly see patients who are brought here in crisis and have to start dialysis immediately – it's not a good thing.' According to Dr Safronov, surgeon at the transplantation unit in Riga, 75 to 80 per cent of the patients start dialysis in this way. The main reason for this, he argues, is the 'stupid system' of primary care that was introduced in Latvia after independence, in which general practitioners are responsible for referring patients to specialists. The general practitioners generally lack sufficient knowledge about kidney disease, Dr Safronov contends, which prevents timely detection and prevention. In his view, the Soviet system in which primary care was provided in polyclinics and all specialists were gathered under the same roof was preferable.

What happens when patients start dialysis in the wrong way, Dr Liepa tells me, is that neither their body nor their self is prepared properly. There

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[30] In Latvia and Sweden both, persons in need of renal replacement therapies are guaranteed free access to dialysis.

is no time to make a fistula,[31] which is the preferred mode of access to the patient's bloodstream. Instead, one has to settle for a central dialysis catheter (CDC),[32] which is more susceptible to infection and has a shorter lifespan. Further, dialysis started in the wrong way precludes any participation by the patient. 'When it's an emergency the patient has to agree […]. He doesn't have a choice, and that's the wrong way,' Dr Liepa says. She continues, 'It's better if you allow the patient to participate in the decision about what kind of procedure he wants […]. If he's working or planning his future activities, for example, it's very important to take different kinds of renal replacement therapies into account.'

Merely by looking at Dr Liepa's characterisation of the incorrect way of encountering dialysis it is possible to tease out clues to what she would consider the correct way. First of all, time is an essential aspect. For there to be enough time, however, there needs to be an early detection of the disease. Here we return to the problem of unskilled general practitioners. What is required, according to Dr Liepa, are family doctors who 'know all about their patients [laughs]', who, are able to 'see small changes […] – I don't know, high blood pressure or changes in the urine tests or higher levels of creatinine[33] than normal…'. But this is not enough. The family doctor also needs to be able to connect these small changes with kidney dysfunction, Dr Liepa argues, and refer the patient to a nephrologist who, from then on, regularly monitors the progression of the disease. This creates time for preparing the body and self of the prospective dialysis patient and allows him or her to participate in the decision-making process. The person with kidney failure may thereby 'start dialysis as a pre-planned procedure, which is the right way to start dialysis,' Dr Liepa says.

Although, during my fieldwork in Stockholm, I did not meet anyone who explicitly distinguished between right and wrong ways of starting

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[31] A fistula is a surgically constructed vascular access, ordinarily located on the patient's forearm, which is created by connecting an artery and a vein (Wikström 2004, 216).

[32] When a central dialysis catheter is used, access to the patient's bloodstream is achieved by means of a catheter that is inserted into the patient's chest (Wikström 2004, 216).

[33] Creatinine is a waste product generated from muscle metabolism. All of the creatinine that is produced in a healthy person's body is filtered out by the kidneys. Consequently, the level of creatinine is often used to measure kidney function (Granerus and Ekelund 2004).

dialysis, most medical practitioners I met seemed to share Dr Liepa's view that a good start is a carefully prepared and planned start. This was evident, for example, when I interviewed one of a growing number of kidney failure coordinators, as they are called. Indeed, the mere existence of kidney failure coordinators is indicative of the weight that is put on the preparation and participation of the patient before the initiation of dialysis. Their main tasks are to inform, educate, and guide patients so that they may feel involved, make informed choices, and maintain physical and psychological well-being before renal replacement therapy is initiated.[34] Kerstin, the kidney failure coordinator whom I interviewed, emphasised the importance of being patient-centred, which, according to her, entails establishing relational ties that enable the patients' wishes and concerns to be heard. This way, Kerstin asserted, she is able to inform and educate them on their own terms. Nonetheless, she still wants them to 'know as much as possible'.

However, as at the unit in Riga, not all cases of kidney failure are detected before dialysis has to be initiated. In Stockholm, though, this number is much lower than in Riga. Instead of 70 to 80 per cent, 20 to 30 per cent of the patients who come to the hospital have to start dialysis immediately. On such occasions, Kerstin tells me, her coordination work begins after the treatment has been initiated. Among the patients in Stockholm whom I interviewed during my fieldwork, no one told me about having met a kidney failure coordinator before undergoing the treatment for the first time. This, I believe, is due to the fact that this position was only recently established. At the hospital where most of the participants in this study encountered dialysis for the first time, a kidney failure coordinator with the work tasks described above was not employed until 2011. However, several of the patients I interviewed in Stockholm had participated in 'kidney courses' or information meetings before encountering dialysis for the first time.

It is interesting to note that the ideal of a prepared and participating patient, strikingly evident above, is so clearly present in Riga and Stockholm both. This is indicative of the transnational spread and presence in

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[34] See the website of the Swedish Nephrology Nurses' Association at http://www.snsf.eu/arbetsgrupper/njursviktssjukskoterskanjursviktskoordinator/, accessed 2015-07-16.

renal care of the ideal of the ‘new’ empowered and autonomous patient, which I mentioned in chapter 1. ‘Clinical medicine,’ Rose writes, ‘increasingly over the last half of the twentieth century, constituted the patient as an “active” subject – one who must play a part in the game of cure’ (2007, 110). This new patient must play this part responsibly and knowledgeably, in order that informed choices may be made, control may be regained, and personal desires and needs may influence the care provided (Hansson 2006; Mol 2008; Svenaeus 2011; Gunnarson 2012). The existence of this ideal clearly attests to the non-neutral character of medicine and medical practice. That there exists a right way of encountering dialysis is not a neutral scientific fact but a morally charged ideal that goes far beyond the medical realm, comprising processes on the level of policy and government as well as on the level of the individual. As such, and as I have already pointed out with reference to Rose above, it is intimately linked to the neoliberal currents that have washed over the world since the 1970s (Fioretos 2009; Svenaeus 2011; Alftberg and Hansson 2012). I will discuss this new role of the patient and its connection to neoliberalism further in the sections and chapters that follow.

In Dr Liepa’s and Kerstin’s accounts above, it is clear that the way of encountering haemodialysis that both of them favour implies a particular type of patient, a ‘new’ patient in the sense described above. This patient not only aligns him- or herself with the diagnostic line established but also informs him- or herself about the various renal replacement therapies available, and does so in a way that makes informed choices possible. This way, Dr Liepa and Kerstin argue, a practically, emotionally, and bodily prepared patient is created. But, as we saw in the previous section, such alignments do not follow as automatic results from the information provided during a diagnostic event. The diagnostic and prognostic information does not constitute neutral facts that patients incorporate unchanged into their corporeal schemas. Instead, they interpret, assess, and react differently to them – thereby altering them – all from the point of view of their particular embodied being-in-the-world (cf. Toombs 1992; Mattingly, Grøn, and Meinert 2011). This is also the case when it comes to patients’ first encounter with haemodialysis. How they experience this encounter depends on the embodied orientation with which they enter the haemodialysis unit, an orientation that is not only, if at all, the result of the preparatory measures taken by medicine. The lines established by diagnosis, prognosis, and various preparations might not afford patients the means necessary to manage their encounter with the treatment.

The latter was the case for Rune. Despite the fact that he had grown used to the thought of having to rely on renal replacement therapies for the rest of his life during the decade that separated the diagnosis and the initiation of haemodialysis, his first encounter with the treatment was 'somewhat shocking', as he describes it. His caregivers had overlooked informing him about the treatment practice and what complications might occur, especially during the very first treatment, when the fistula is punctured for the first time. A couple of months before the initiation of haemodialysis a fistula had been made in Rune's arm. 'So I was prepared in that way,' he says. He had also made an agreement with his employer to adapt his working hours so that he could continue to work full-time even though he would be undergoing haemodialysis twelve hours a week. As had been planned, he arrived directly from work for his first treatment. 'At that time you wore a white shirt and tie,' he says and laughs, because what happened next was that when the head nurse inserted the first needle, blood sprayed everywhere, all over his shirt and tie. For Rune, the fact that he had not changed clothes before the treatment illustrates how badly informed he had been. 'I knew that I was supposed to start with this [haemodialysis] and I knew in theory what it was going to be like, but it was a bad start,' he says. Thus, although he had oriented himself in line with the diagnostic line and, in the view of his caregivers, most likely lived up to the ideal of the prepared and participating patient – starting the treatment in the right way – Rune's first encounter with haemodialysis was a rather disorienting one.

Veronica was probably also considered by her caregivers to be a prepared and participating patient. In 2001, when she was forty-six, Veronica noticed that her feet were swollen, and she interpreted this as caused by her new, ill-fitting sneakers. When the swelling did not recede but instead moved upwards and she began to have trouble breathing, she understood that something was wrong and went to her family doctor, who immediately referred her to a specialist at the hospital. Now a quite protracted diagnostic process commenced, during which Veronica was hospitalised.

After about a week, she was diagnosed and was told that her kidneys would eventually fail and that she would require renal replacement therapies. At this time Veronica was in shock, she tells me. She was supposed to start a new job, something she had been looking forward to a lot, and did not want to hear that something was wrong with her. But her hospitalisation continued, and it was not until a month had passed that she was well enough to begin her new job. But she was not well. She was on medication and never managed to work full-time at the new place. However, it would still be two years before she had to start dialysis. 'So you were prepared for this to some extent?' I ask her. 'Yes, I knew, I knew…,' she replies. 'First I tried to, "No, I don't want to start now," when they told me [it was time], despite the fact that I knew that it would come to that. But then I said to myself, "I can't manage any longer, I want to start."' At this time, Veronica's health was badly affected by the excess fluid that had accumulated in her body and she hoped that haemodialysis would alleviate her suffering. But encountering the treatment for the first time was difficult. This is how she describes the preparatory measures that had been taken, and how she felt before undergoing haemodialysis for the first time:

> I had visited [a haemodialysis unit] and I think, no I don't remember, but I think I went to a course, too, something they gave for people who were starting dialysis. But I was afraid; I was afraid. Even though they said, 'It doesn't hurt, it's not painful,' and things like that. But… the biggest fear was the needles…

The preparatory measures taken before Veronica started haemodialysis were incapable not only of eliminating her fear. They were also unable to answer her 'biggest question', namely 'how it would feel'. Indeed, her uncertainty about whether she attended a course before her first encounter with the treatment itself indicates that, if she did attend such a course, it did little to diminish her fear or answer her questions.

Unfortunately, Veronica's first encounter with haemodialysis was not good. So much water had accumulated in her body that the treatment initially did not work. 'It seems like the more fluid you have, the harder it is to get it out,' she says. As a result, she initially had to undergo the treatment every day, which was a very difficult experience for her. Fortunately, the nurses were kind and helpful and supported her through this difficult time. In sum, what Veronica's account reveals is that the preparatory and participatory measures taken by renal care specialists to ensure that patients start haemodialysis in the right way might not afford them an orientation that prevents them from experiencing their first encounter with the treatment as disorienting.

For Camilla, it was becoming oriented as a patient within the spatiality of the haemodialysis unit that most affected her experience of encountering the treatment for the first time. Just like Rune and Veronica, Camilla started dialysis in what, from a medical point of view, would be considered the right way. She was thirteen years old when she was diagnosed with chronic kidney disease and told that she would eventually require renal replacement therapy. Camilla's parents took her to the doctor because she was suffering from severe fatigue. 'I remember', she says, and continues:

> I was so tired, you know, that I could barely stand. I just lay down and still I couldn't sleep. That's a weird feeling. But then, when they had found the cause [Camilla does not remember the name of her diagnosis] and began treating it [with medications], I felt pretty well, I think, the years between [the diagnosis and the initiation of haemodialysis]. Then it's like the last year before dialysis that you start to feel worse.

Camilla was nineteen when she underwent haemodialysis for the first time. Before this she had made a couple of visits to the unit where she was going to undergo the treatment and had been shown a video about how it worked. Since Camilla had just entered adulthood at the time, it is perhaps unfair to contend that she was prepared and aligned with the diagnostic and ideal-patient lines to the same extent as Rune and Veronica. But, taking her age into account, she was prepared in the sense that she knew what was going to happen and had received information about what this would entail. Thus, considering the circumstances, Camilla started dialysis in the right way. Even so, it was a difficult start. This is how she describes it:

> I was pretty shocked, actually, since what you enter is a hospital. It's a big difference between going to the unit we have here [the self-care unit] and going to a hospital unit. So you come in there [to the hospital unit] and see all the people who are lying there feeling awful and, you know, lying in a bunch of beds and there is staff and stuff. So at that time it was a little bewildering…

During our conversation Camilla often contrasts her first experience of haemodialysis to her later experiences of managing the treatment by herself at the self-care unit and at home. At the hospital unit where she first encountered haemodialysis, her fellow patients were old and severely ill, and several nurses were involved in managing her treatment. This made it all very dramatic, she tells me, and contrasts it to the present when 'it's not such a big deal anymore'.

It is interesting to note that the treatment spatiality did not emerge as dramatic and shocking to Camilla until she was, herself, oriented as a haemodialysis patient within it. She had visited the unit before, but it was when she underwent the treatment for the first time herself that her resemblance to the other, sicker, patients, and the drama of having several nurses in 'aprons and gloves' manage the treatment, really dawned on her. In aligning herself with the line of a haemodialysis patient Camilla extended into the spatiality of the unit in a new way, a way that affected how she experienced the objects and others in that space, and herself through them. Rather than experiencing herself as oriented, in the sense of feeling at home, she was disoriented by this alignment. She had been hailed in line with the orientation of a haemodialysis patient and, as a result, she was not yet fully oriented in a way that made the line disappear into the absence of her corporeal schema. Camilla knew that she would soon be transplanted with one of her mother's kidneys, but the year it took before this happened, during which she underwent haemodialysis, was characterised by the disorienting presence of haemodialysis in her life.

I will analyse the meaning of the treatment spatiality more thoroughly in the next chapter (see also Gunnarson 2011). At present, I wish to present yet another example, adding to the complexity characterising the participants' first encounter with haemodialysis. When Hans, eighteen years after he was diagnosed with chronic kidney disease, began to experience symptoms, he begged his caregivers to allow him to start dialysis. When I ask him why, he refers to the symptoms of illness he had been experiencing. He was constantly breathless and tired, and his legs felt like cement. He was also unable to work. 'Everything was crappy,' he says, 'so I thought, "Why the hell should you wait just because they [the doctors] want to reach their percentage?"' What Hans is referring to here is the kidney function measured in per cent at which, according to medical guidelines, renal replacement therapies should be initiated. Fortunately, Hans's begging paid off and he was permitted to start haemodialysis before he had reached the specified percentage. He did not, however, like the unit where he was initially placed, at which the nurses managed the treatment for him and where he was forced to lie in a bed. Fortunately, after only two weeks he got to move to the self-care unit, where he has managed his own treatment since.

Hans was only twenty-five when he received his diagnosis. But, like Rune, he did not experience this as shocking since he had plenty of time to 'psychologically get used to the thought [of undergoing haemodialysis]', as he puts it. Much like Rune, Hans quickly aligned himself with the diagnostic line and followed the slow deterioration of his kidneys by means of the results of his regular medical check-ups. In 2005, two years before he underwent haemodialysis for the first time, a fistula was made, and close to the initiation of the treatment he made a visit to a unit.

When he started the treatment in 2007, he was not afraid at all, he tells me. Haemodialysis was what he had expected. This absence of fear, Hans contends, is due to his personality, and to the way previous experiences have shaped it. He is a realistic person, he tells me, and continues, 'I mean, you take each day as it comes. And it could have been worse, if there hadn't been anything, just "Have you written your will?" which wouldn't have been much fun.' This realistic way of being, he asserts, is a product both of the way he was raised and of his extensive experience of acting and touring with his choir. His artistic experiences, in particular, have provided him with an ability to improvise and adapt flexibly to unexpected situations, and made him a cheerful and easy-going person, he tells me. All of which are traits that enabled him to say 'Take it, take it,' to himself, to 'just go hat in hand and get in line' when haemodialysis was initiated. What enabled Hans to orient himself in line with the diagnostic, prognostic, and treatment lines was thus primarily the nature of his personality. But Hans's rather positive experiences of encountering haemodialysis for the first time also hinged on the capacity of the treatment to alleviate his illness symptoms, to take him out of or at least dampen his unhomelike being-in-the-world. Had he experienced a difficult start, like Veronica's, his personal traits might not have sufficed to reorient him (cf. Kierans 2005).

The importance of the capacity of haemodialysis to alleviate the unhomelikeness experienced by patients before they undergo the treatment for the first time becomes strikingly evident when it is initiated in what medicine would consider the wrong way. As we saw above, the severe unhomelikeness that Ivan suffered before he finally got to meet a specialist and was connected to a haemodialysis machine made him feel indifferent. He thought that he was going to die and did not care what measures the doctors took to save his life. What occupied his mind was not how it was going to feel to undergo haemodialysis – he did not even know that he would – but whether or not he was going to survive. When the treatment was finally initiated for the first time it had an immediate effect. 'They connected the device, and I felt good. I started to feel amazing immediately,' he says. Compared to the extreme suffering and near-death experience that he had before it was initiated, Ivan thus remembers his first encounter with haemodialysis in quite positive terms.

Dmitry had a similar experience. In 1996, when he was twenty-five, he went to the doctor because his 'vision had changed for the worse'. At the polyclinic, which was still operative at the time, an ophthalmologist examined him and detected an inflammation of his optic nerves, for which he was prescribed antibiotics. But the ophthalmologist wanted to investigate the cause of the inflammation further, and by Dmitry's third or fourth visit to the polyclinic his condition had vastly deteriorated. Now he was in such a bad state that the doctors deemed it necessary to send him by ambulance to one of the larger hospitals in Riga, where he underwent a diagnostic procedure that lasted two weeks, during which his condition deteriorated even further. Finally he was diagnosed and sent to yet another hospital, where haemodialysis was immediately initiated. 'At that time', Dmitry tells me, ‘I was in such bad condition that I was totally indifferent. Why? Because I had overall body poisoning, and dialysis naturally relieves that. You start to feel much better and, of course, because of that you’re not afraid.’

For Dmitry, as for Ivan, haemodialysis brought relief from the severe unhomelikeness he experienced prior to its initiation, and this alleviation greatly affected how he experienced encountering the treatment for the first time. Rather than being shocking and disorientating in itself, haemodialysis facilitated an escape from the disorientation he experienced.

With the accounts above I have aimed to illustrate and highlight the complex contextual and situational character of the participants’ first encounter with haemodialysis. As we have seen, this complexity goes beyond the medical notion, represented above by Dr Liepa and Kerstin, of what constitutes the right way of starting the treatment. What the accounts above show is that a person’s orientation in line with the diagnostic and ideal-patient lines does not eliminate the risk of disorientation. Sometimes the practicalities of the treatment do not run as they should; sometimes a feeling of fear persists despite the caregivers’ repeated reassurances that it will not hurt; sometimes the treatment reinforces the unhomelike illness symptoms experienced rather than alleviating them; sometimes the presence of the other, sicker patients and the activities of the nurses amplify the drama of the treatment; sometimes personal traits are, if not more important than, then at least equally as important as one’s orientation in line with the diagnostic and ideal-patient lines.

What my empirical material does not suggest, however, is that encountering haemodialysis in the right way – as Dr Liepa and Kerstin define it – affects a patient’s experiences negatively. The preparatory and participatory measures taken when a person is aligned with the diagnostic and ideal-patient lines do not have adverse effects. They may, for example, and probably often do, help patients get used to the thought of having to undergo haemodialysis and enable them to come to terms with the treatment more quickly after its initiation, as was the case with Rune and Hans. But they are not sufficient to guarantee that patients’ experiences of their first encounter with haemodialysis are not disorienting.

It is easy to agree with Dr Liepa and Kerstin that Ivan and Dmitry started haemodialysis in the wrong way. Both of them were so ill that they felt indifferent, not caring what happened to them. That Dr Liepa and Kerstin, knowing that many such cases can be detected in advance, view these as failures is therefore not surprising. But what Ivan's and Dmitry's accounts illustrate is that a medical technology's ability to alleviate an experienced unhomelikeness may greatly influence how patients experience their first encounter with it.

Encountering kidney transplantation

A while into my fieldwork I realised that I had forgotten to pose an important, if not essential, question. I realised that I had not asked the persons with kidney failure whom I interviewed the simple question *why* they wanted to be transplanted. This realisation told me that, unreflectively, I had assumed the answer to this question to be self-evident. I had thought it unnecessary to thoroughly explore the motives and desires behind a person's willingness to undergo organ transplantation. Of course they wanted transplantation, I had unreflectively assumed; it is, after all, the best treatment. Fortunately, my conversations with the patients had, without my asking the question outright, revolved around this issue, thanks much to their own desire to discuss it. In fact, this was how I discovered my blunder. In going through the interviews I had conducted during my first trip to Riga, I realised that the motives and desires orienting patients' attitudes towards and choices in relation to organ transplantation were often far from self-evident. Instead, these were themes they themselves felt needed to be addressed.

Consequently, when I returned to Riga for my second visit and subsequently began to conduct interviews in Stockholm I asked all persons I met who were undergoing haemodialysis why they wanted or did not want to undergo transplantation. From the accounts this question spurred, and from the previous, unprompted accounts, I began to see a pattern emerge. It turned out that the patients' orientation towards transplantation tended to shift quite drastically after they had undergone it. This is not a finding I can take all the credit for. Many of the persons I interviewed who had undergone one or more transplantations were themselves aware of and eager to discuss this shift.

Since what I am concerned with at the moment is the participants' first encounter with the transplant alternative, my primary focus in what follows will be on their experiences and their views prior to this shift. I will return, in chapter 7, with an exploration of the ways in which these experiences and views shifted after they had undergone the procedure. In order to put empirical meat on the bones of the shift I am referring to here, however, I will begin by presenting two of the participants' descriptions of this shift.

After having undergone transplantation once, Sven decided not to opt for a second one. The main reason for this was the 'toxicity', as he puts it, of the immunosuppressive medications he had had to ingest while he was transplanted.[35] He did not want to risk experiencing any of the serious complications listed on the leaflet accompanying the medications and felt that he could live a fairly good life with haemodialysis. Prior to the transplantation, however, he had seen it as 'the big wonder'. When he received the call that there was an organ for him, he had been happy and felt that 'it was like winning the top prize in a lottery'. 'I had dreamt of this,' he tells me, 'because they had promoted it in a way. So receiving a new kidney was my dream, and [I dreamt] that life would then really open up itself, forever almost.' 'But then I realised that it wasn't exactly like that,' he continues, 'but that was after I had received the transplant.' Sven's transplant functioned for nine years, but never perfectly. The level of creatinine in his blood was always somewhat high, which affected his feeling of health. But, for him, what was worse were the potential side effects of the immunosuppressant drugs. It came as a surprise to him that these medications were so toxic. No one had told him about this before the transplant, he claims, implying that he would not have gone through with the procedure had he known about it.

In Sven's story, the shift in orientation is striking. He goes from viewing transplantation, prior to the procedure, as a wonder capable of opening up his life perpetually, to viewing it, after having undergone it, as inferior to

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[35] In order to counter the immunological response, the acute or chronic rejection that invariably commences when a person undergoes organ transplantation, recipients are prescribed a host of immunosuppressive medications that they have to take until their transplant ceases to function (Tufvesson 2004, 241–242; Sharp 2006, 247–248).

haemodialysis due to the toxicity of the immunosuppressive drugs. A similar shift in orientation is evident in Filips's story. When I meet Filips in late 2009 and early 2010, he has undergone three transplantations, none of which has given him the kind of life he has expected. 'It was easy to undergo the first transplantation,' he tells me. 'I thought, "Finally everything will be good." But it only worked three years.' When the doctors offered him admittance to the waiting list for a second transplantation, he accepted the offer. But he was aware that the chances of success were smaller this time.[36] And when his body acutely rejected the transplant, he began to wonder, 'How long will the third transplant function?' The answer to this question was two years. But neither the first nor the third transplant functioned without complications; on a couple of occasions he even had to undergo haemodialysis in order to support their function. At the time of our conversations, Filips is uncertain about whether he should opt for a fourth transplant. 'I'm considering continuing with dialysis,' he tells me, 'because I understand that it's almost impossible to find a 100 per cent matching kidney. And for the fourth, the level of compatibility is very low.'

For Filips, unlike Sven, the shift in orientation towards transplantation was gradual. With every attempt, he successively lowered the expectations he attached to it. While initially expecting transplantation to make everything good, he became more and more concerned with its limited duration, and finally, after the third attempt, was dubious about whether he should put himself on the waiting list for a fourth attempt in the event that he was offered the opportunity.

Taken together, Sven's and Filips's accounts exemplify a complexity that I wish to highlight to some extent here, but even more so in chapter 7. What is striking in both of their stories are the high expectations they initially attach to transplantation, before they undergo the procedure for the first time. Why do they do so and where do these expectations come from? These are the questions I intend to answer in the following. In doing so I will first return briefly to the dominant discourse on organ transplantation that was mentioned in chapter 1.

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[36] According to medical research, the 'graft survival', that is, the time that the transplant survives in the recipient's body, is lower in retransplantations (see Ahmed et al. 2008).

The straightforward lifesaver and normaliser

Since the first successful kidney transplantation was performed in Boston in 1954, and since the South African surgeon Christian Barnard performed the first successful attempt to transplant a heart in 1967, organ transplantation has developed into a routine treatment for organ failure. An important breakthrough in this process of routinisation was the introduction on the market in the 1980s of the immunosuppressive drug Cyclosporine, which radically improved the outcome of the procedure, made the cross-matching between donor and recipient less complicated, and prolonged the function of the transplanted organ by holding off the chronic rejection that always commences when an organ changes bodies (cf. Fox and Swazey 1992).

These advances, as I pointed out in chapter 1, have laid the foundation for a view of organ transplantation as 'one of the most remarkable medical inventions' (Ambagtsheer, Zaitch, and Weimar 2013, 2) and 'great medical miracles of the 20th century' (Monaco 2007, 89). As several humanistic and social scientific researchers have shown (see e.g. Crowley-Matoka 2005; Kierans 2005; Sharp 2006; Waldby and Mitchell 2006), this view has become immensely widespread and currently constitutes a powerful discourse orienting the views and experiences not only of those who are directly involved in the transplant practice but also of the public in general. According to this discourse, the remarkability and miraculousness of organ transplantation consists in its simultaneous and routine lifesaving and normalising capacity (Quante and Wiedebrusch 2006; Pomfret et al. 2008; Omar, Tufvesson, and Welin 2010). Organ transplantation not only saves recipients' lives, it tells us, but it also facilitates their return to a normal life, and achieves this by fairly routinely applying its healing powers (cf. Crowley-Matoka 2005; Moniruzzaman 2012). Framed in this manner, Kierans points out, transplantation is conceptualised as an 'end game', as a cure, as the successful end to a protracted struggle against disease and death (2005, 345). The pervasiveness of this conceptualisation was evident in Sven's and Filips's accounts above. Sven, for example, expected his life to 'really open up itself, forever almost' after transplantation.

The following is an example of how this dominant discourse on organ transplantation is articulated in the scientific literature – and here I cite the three bioethicists I quoted in chapter 1: 'For many patients receiving a healthy kidney is a second chance at a normal life, a possibility to get back into society, and [pursue] their dreams, to shed the sick role, and rediscover their former livelihood' (Omar, Tufveson, and Welin 2010, 94). Portrayals such as this are not confined to the scientific sphere. They reach public consciousness, for instance, through various organ donation campaigns,[37] through traditional and social media,[38] and through events such as the World Transplant Games.[39] The Swedish Council for Organ and Tissue Donation,[40] for example, posts interviews with organ recipients concerning their life after transplantation on its website. Madeleine, who has undergone heart transplantation, is said here to 'live a normal life'. What this means is revealed by the words that follow, which inform the reader that she 'hangs out with her friends and goes out partying', and that 'she works as an auxiliary nurse'.[41] In short, then, what the dominant discourse on organ transplantation – of which the examples above are merely a couple of manifestations – tells us is that an orientation towards transplantation is an orientation towards a healthy and normal life. By receiving a transplant, we are told, one may become the person one once was, thereby escaping the patienthood that one was thrown into when one fell ill.

It would be extremely unfair to claim that the image of organ transplantation conveyed through this discourse is completely unwarranted. There

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[37] In Sweden a campaign initiated by the Federation of County Councils and the Ministry of Health and Social Affairs with the aim of increasing the public's awareness of and generating a positive attitude towards organ donation was launched in 2003 (Krekula et al. 2009). Under the slogan 'When you need one, you'll understand', the Latvian Transplantation Center and the Pauls Stradins Clinical University Hospital launched a similar campaign in November 2014, see http://www.lsm.lv/en/article/societ/society/public-urged-to-sign-up-as-organ-donors.a106255/, accessed 2015-07-29.

[38] In the Swedish context, the NGO 'MOD – mer organdonation' (more organ donation) has been particularly successful in raising awareness about the benefits of organ transplantation and the importance of organ donation by means of social as well as traditional media, see http://merorgandonation.se/, accessed 2015-07-29.

[39] See http://www.wtgf.org/, accessed 2015-07-29.

[40] http://www.livsviktigt.se/Sidor/default.aspx, accessed 2015-07-16.

[41] http://www.livsviktigt.se/Personligaberattelser/Sidor/madelaine.aspx, accessed 2015-07-16.

is ample evidence in the medical literature confirming the beneficial nature of organ transplantation. The question is whether the results of this research actually support the claims that are made on their basis. In the medical literature, the efficacy of organ transplantation is primarily measured in terms of survival rate or mortality (see e.g. Lodhi, Lamb, and Meier-Kriesche 2011; Tonelli et al. 2011). In the context of kidney transplantation, this generally results in a practice where the survival rate of transplanted patients is compared to that of patients on dialysis. As Tonelli et al.'s (2011) review of the literature on the results of such comparisons reveals, when measured in terms of survival rate or the risk of mortality, the superiority of kidney transplantation compared to dialysis is unmistakable. '[The] cumulative mortality associated with transplantation was significantly lower than among patients with dialysis,' they found, a finding that leads them to conclude that 'kidney transplantation is the preferred modality of treatment for chronic kidney failure' (Tonelli et al. 2011, 2103).

This evidence is convincing. But does it support the conceptualisation of organ transplantation as the lifesaving end to a struggle against disease and death? No, it does not. It merely tells us that the risk of mortality is considerably lower for transplanted patients than for patients on dialysis. The matters become even more complicated when the concept of 'graft survival' is added to the analysis (see Matas 2004; Lodhi, Lamb, and Meier-Kriesche 2011). This concept denotes the time that a transplanted organ functions in the body of the recipient. Making the distinction between mortality and graft survival is particularly pertinent in kidney transplantation, since when a transplanted kidney ceases to function most patients are able to go on living with dialysis. In kidney transplantation, therefore, the loss of a transplant seldom coincides with the death of the patient. What the research that makes use of graft survival as the mode of measurement illustrates is that the survival of a transplanted organ is not permanent (see e.g. Lamb, Lodhi, and Meier-Kriesche 2011). Sooner or later the graft stops functioning, a finding that speaks against the conceptualisation of organ transplantation as a lifesaving end to disease.

In addition to mortality and survival rates, the efficacy of organ transplantation is often evaluated in terms of quality of life (Joralemon and

Fujinaga 1996). But rather than utilising a qualitative methodology themselves, these studies employ prefabricated questionnaires, such as the World Health Organization Questionnaire on Quality of Life (WHO-QOL) (Niu and Li 2005), and report their results quantitatively, in Quality Adjusted Life Years (QALYs), for example (Matas and Schnitzler 2003). Consequently, although they confirm the superior quality of life of organ recipients compared to persons living with dialysis (see e.g. Landreneau, Lee, and Landreneau 2010), these studies generally do not reach the qualitative depth necessary for determining whether or not the research subjects experience health in the sense of a homelike being-in-the-world or normality in all its cultural and normative manifestations (cf. Joralemon and Fjinaga 1996). Yet quality of life measures are often used as indicators of the health and normality experienced by organ recipients. It is, for example, under the heading '*Quality of Life*' that Omar et al. write about the shedding of the sick role and the return to a normal life that they contend take place when a person receives a transplant (Omar, Tufveson, and Welin 2010, 94).

From a medical point of view, then, kidney transplantation is without a doubt a better treatment than dialysis. It substantially reduces the risk of dying and significantly increases the quality of life. But what I have wanted to highlight above is that when this superior survival rate and quality of life are linked to powerful concepts such as health and normality, promises are made that may be difficult, if not impossible, to keep. In promising health, normality, and survival, the pervasive discourse that is created affects not only the general public's view of organ transplantation, but, as Sven's and Filips's accounts above illustrate and as we shall see below, it also fundamentally affects the expectations that prospective organ recipients have for the procedure.

Expecting survival, health, and normality

As the above exposition illustrates, organ transplantation is a highly morally and normatively charged biomedical therapy. As such, it constitutes a line, in Ahmed's sense of the term, that is possible for persons undergoing haemodialysis to follow. This line promises a particular return. By practically and emotionally orienting themselves in line with this line, and thereby reproducing its norms and values, persons requiring renal replacement therapy are promised a return in the form of health, normality, and survival (cf. Ahmed 2006, 17). In what follows, I refer to this line as the dominant line or orientation towards transplantation.[42]

Clearly, this is the line that Sven and Filips followed prior to undergoing transplantation for the first time. In expecting life to open itself up forever and everything to finally be good after transplantation, they had both invested themselves in the promises attached to the procedure and aligned themselves with its morality and norms. At the beginning of my fieldwork, I shared this alignment. Like Sven and Filips, I saw the willingness to undergo transplantation as self-evident, even to the extent that I unwittingly avoided addressing the issue, a blunder that attests to the pervasiveness of this line beyond the realm of medicine.

Among the persons with kidney failure whom I interviewed during my fieldwork, Sven and Filips are far from alone in being oriented in this way prior to undergoing organ transplantation for the first time. When I ask Marianne what she had been thinking and feeling before the first of her two transplants, she says, ‘Well, it was the saviour. It was, oh, it was… transplantation was like “Yes!” then everything would resolve itself.’ Lidija had had similar thoughts and feelings. She had imagined that she would live ‘like normal people’ after transplantation, while Liouba, who at the time of our conversations is waiting for her first transplant, tells me, ‘We [the patients] don’t discuss transplantation, since it’s certain that you want to undergo it.’

In Pyotr’s story the expectation that organ transplantation will bring about a return to a normal work and family life is strikingly evident. When

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[42] Since, as I write in chapter 1, my focus in this book is on the ‘life’, rather than the ‘gift’, aspect of kidney transplantation, I do not conduct a thorough exploration of the donor–recipient relationship. This relationship is well documented in previous research, where recipients’ often complex and emotionally charged bonds to both living donors and deceased donor kin has been addressed and analysed (see e.g. Fox and Swazey 1992; Sharp 1995; Lock 2002; Waldby 2002; Sanal 2011; Shildrick 2012. 2013). In chapter 7, however, I make a brief foray into the participants’ attitudes towards and experiences of living-donor kidney transplantation, focusing particularly on the way in which these attitudes and experiences relate to medical conceptions of the procedure.

he receives a transplant, he tells me, 'I will pay more attention to my family' and 'have a normal job'. At the time of our conversation, Pyotr is waiting for his first transplant and is affected badly by haemodialysis. He describes the days with the treatment as lost because he is so tired after spending four hours at the machine that he has to go home and go straight to sleep. Under these circumstances his ability to attend to his family – his wife and their two children – and to work is greatly reduced. But he is convinced that he will regain these abilities following transplantation. It is clear during our conversation that it is not primarily a feeling of hope that orients him towards transplantation, but a firm conviction that the procedure will enable him to attend more to his family and to have a normal, full-time job (cf. McKevitt, Luse, and Wolfe 2003). This echoes the findings of Crowley-Matoka (2005). In her study of organ transplantation in Mexico, Crowley-Matoka found that the main promises attached to the procedure had to do with regaining a reproductive and productive life. Following transplantation, the prospective organ recipients learned, they would reclaim their capacity to contribute fully to their family and hold a regular job (Crowley-Matoka 2005, 826).

Besides normality, health, and survival, the persons I interviewed during my fieldwork also describe their expectations of transplantation in terms of freedom. Eva, who at the time of our conversation is hoping to be admitted to the waiting list for her first transplant, does so, for instance, and so does Pyotr, whom we met above. At stake in their accounts are both a 'freedom from' and a 'freedom to'. Eva tells me that she simultaneously desires freedom from the haemodialysis machine and being free 'to do something you want to do every day, go on vacation without needing guest dialysis, things like that'. In Pyotr's account it is evident that the 'freedom to' presupposes the 'freedom from'. 'Kidney transplantation delivers freedom in a direct sense,' he says. 'You have to take medications […], but you're not bound to a place, which you are now.' Gaining freedom in a more general sense thus hinges on a freedom from the haemodialysis machine. Since it is to a great degree the haemodialysis treatment that has deprived Eva and Pyotr of their sense of freedom, they have a strong desire to escape this form of treatment. But this 'freedom from' also hinges on the 'freedom to' that organ transplantation promises. It is because the alternative to haemodialysis, transplantation, is seen as capable of bringing about a life where one can engage in activities of one's own choosing and increase one's mobility that an escape from haemodialysis is so desirable. Thus, for persons with kidney failure, the dominant line towards kidney transplantation gains its strength not only from the promises attached to organ transplantation but also from what they experience on haemodialysis.

In the Swedish context especially, the information coming from the doctors contribute a great deal to the patients' alignment with the dominant line towards transplantation. At the time of my conversation with Tomas in February 2011, he is hoping to be admitted to the waiting list. Having reached the age of sixty-four, he has been informed by the doctors that if he does not lose seventeen kilos before he turns sixty-five he will not be deemed eligible for transplantation. Losing this weight is a struggle for Tomas, and it is evident during our conversation that he is frustrated about this and that he is not certain he is going to make his deadline. But he is not about to give up, and he can convincingly explain why through a concise and forceful statement: 'Well, they [the doctors] promise me fifteen to twenty years of normal life after it [transplantation].' What is keeping Tomas in line with the dominant line towards transplantation, and what makes his struggle to do so meaningful and self-evident, is the promise of a normal life given to him by his doctors through a snappily formulated statement.

But the absence of essential pieces of information may also serve to reinforce the alignment of haemodialysis patients with the dominant line towards transplantation. Camilla describes the consequences of such absences expressively:

> I remember that no one told me in plain language that you will end up on dialysis again. So I had my fistula removed. I had no idea that you should save it, because it's good to have, since you don't have unlimited resources to build on. No one told me anything about that. I think that's poor treatment. Okay, I was so young that maybe I would have removed it anyway because I thought it was annoying to have it then. But when I get transplanted again I will probably keep it as a safety line.

As I have already mentioned, a fistula is a surgically constructed vascular access in which two of the patient's own blood vessels are connected. While a person is on haemodialysis a functioning fistula is one of the most important – if not *the* most important – aspects of the treatment, since it is what gives the machine access to the patient's bloodstream, and may therefore, as Camilla does, be epitomised as a safety line (cf. Hagren 2004). The fact that Camilla had her functioning fistula removed is thus illustrative of the extent to which she was aligned with the dominant orientation towards transplantation and of how her caregivers supported and reinforced this orientation by failing to inform her about the limited duration of a transplant and the sensibleness of keeping a functioning fistula. To use Ahmed's vocabulary (2006, 17–18), since a 'lifeline' was thrown to her – in the form of an organ – no one acknowledged the fact that Camilla did away with a safety line – in the form of a fistula. In hindsight, Camilla characterises the absence of sufficient information as poor treatment. Someone on the medical staff should have risen above the excitement of performing yet another transplantation and soberly informed her of the fact that in all probability, she would return to dialysis one day and hence would be in need of the valuable fistula, she seems to say.

Many of the patients in Riga also mention such absences of information. Filips, for instance, quite matter-of-factly states, 'Doctors talk less about the fact that it [transplantation] can be unsuccessful.' Having experienced several more or less unsuccessful transplant procedures, Filips has realised that the doctors generally refrain from speaking about all the risks associated with transplantation. Unlike Camilla, however, Filips does not express any dissatisfaction with this. He has simply not expected to be fully informed, and has therefore, like many of the patients at the unit in Riga, made use instead of the knowledge possessed by his fellow patients to inform himself about the procedure.[43]

Unlike Camilla and Filips, Veronica is ambivalent about the absences in the information provided prior to her first and only transplantation. Before she underwent the procedure the doctors knew that there was an imminent

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[43] See Gunnarson (2015) for an exploration of the interaction between patients in haemodialysis.

risk that the transplant would not begin to function in her body. They worried that the disease that had caused her kidneys to fail would attack the transplanted kidney as well. And this was unfortunately what happened. According to Veronica, none of the doctors informed her about this risk before the procedure. At the time of our conversation, she is ambivalent about whether this was good or bad. When I ask her if she thinks she received enough information prior to undergoing the procedure, she says:

> [Pause] That's a difficult question, I think. Because if they start telling you a lot about the fact that it might go wrong, you might get worried, and that's not good either. And […] afterwards I think I had pretty much fun and thought it would go well, like, I was hoping it would go well. Maybe they should've said a little more about the possibility of it not going well… A nurse did, but I didn't want to listen, I didn't want to…

Marianne has a similar view. She tells me that she does not remember if anyone ever told her that transplanted life might not be '100 per cent better' than life with dialysis. 'But,' she continues, 'I don't think you listen that carefully, either. You wanted this [mind-set] that "then I get well […], then everything resolves itself". You wanted to keep it in front of you.'

Thus, Veronica and Marianne both imply that they were to some extent complicit in imagining transplantation as the great saviour (cf. Brown 2005, 344). In hindsight they have realised that they were so eager to align themselves with the dominant line towards transplantation that they closed their ears to information that contradicted it, thereby reinforcing it. As Ahmed points out, through the intentions with which we orient ourselves in the world – intentions that are always situated in a sociocultural context – we tend to arrive at some things rather than others, and some things rather than others tend to arrive at us. Such arrivals, she contends, are in and of themselves performative; they shape what the objects we encounter become, how we come to perceive them (Ahmed 2006, 40; see also Merleau-Ponty 2002, 157). If, like Veronica and Marianne, one is aligned with the dominant orientation towards transplantation, one will perceive the objects one encounters in a certain way. Information about the risks associated with organ transplantation may then, from the point of view of this orientation, be experienced as less important or even meaningless, or it may at least be possible to disregard it, as Veronica's and Marianne's accounts imply.

This dynamic must also be understood from the point of view of the bodily here and now that Veronica and Marianne occupied as patients undergoing haemodialysis while waiting for their first transplant. This is an embodied situation, as the coming chapters will reveal, that is characterised by terminal illness, haemodialysis dependence, and existential precarity. It is a situation in which the prospect of premature death is often painfully present and where gaining a sense of normality requires constant work on oneself and one's body. Further, it is a situation in which one is dependent on the actions and expertise of others, especially medical personnel such as doctors and nurses. One's bodily here and now is thus a vulnerable one, from the point of view of which the return promised by transplantation seems worth investing in. Thus, not surprisingly, persons with kidney failure who are awaiting their first transplant are particularly susceptible to the values attached to the dominant image of transplantation, since it offers them a line promising a return in the form of health, normality, freedom, and survival.

As I argued above, the reproduction of the dominant line towards transplantation is not confined to the realm of medicine; it does not rely just on the information provided or not provided by medical professionals. This is evident in Veronica's story. The transplant she received in 2003 never began to function properly; she was away from dialysis for two years but never experienced the health and normality she had expected. Rather, she felt ill most of the time and depended on the assistance of her caregivers and family. 'I couldn't be happy,' she tells me. 'People might say to me, for example, "But Veronica, you're off dialysis now," implying that I should be happy about this. But when I didn't feel well, I couldn't…'

Here it was people in general, not medical professionals, who expressed ideas about how one ought to feel after transplantation. The idea advanced was that receiving an organ automatically produces happiness in the recipient, an idea that in this instance was very much founded on the dichotomy between dialysis and transplantation that is prevalent in the dominant orientation towards kidney transplantation. What the people around Veronica told her was that, since dialysis is the negative flip side of transplantation, simply being away from it should make a person happy. This echoes Sharp's contention that 'transplant recipients soon learn that even close friends quickly grow intolerant of repeated, drawn-out accounts of their physical, psychic, and economic ills. Many recipients feel, too, that they are not entitled to speak of ongoing forms of suffering because their surgeries have saved (or, certainly, extended) their lives' (2006, 108; see also Kierans 2005, 352).

This notion is further reinforced by the powerful metaphor of the 'gift of life' that is attached to organ transplantation, which exerts a forceful moral pressure on organ recipients to exhibit gratefulness and happiness, despite the hardships they may experience in the wake of undergoing the procedure (see e.g. Siminoff and Chillag 1999; Sharp 2006; Gunnarson 2012). This is one aspect of the 'tyranny of the gift' that Fox and Swazey (1992) write about (cf. Ahmed 2006, 86). In associating the 'gift' so closely with a certain kind of 'life', the 'gift of life' metaphor almost automatically relegates any suffering and complications experienced by the organ recipient to the background. In focusing on the gift that had enabled Veronica to escape dialysis, the people around her oriented themselves away from her sadness and suffering. She *should* be happy, they implied, and in so doing reproduced the line associating transplantation with health and normality.

Veronica clearly experienced this as a form of pressure. Having received a transplant, she felt an obligation to exhibit happiness. But when she did not feel well, she could not. She embodied a body that was impossible to push into line with the dominant orientation towards transplantation. According to Ahmed, it is an aspect of the normative force of lines to exert such pressure (2006, 17). In offering us a homelike alignment with our surroundings, they demand that we extend the line by reproducing it. Interestingly, Ahmed places the following of lines within a form of gift economy. Inspired, like Fox and Swazey, by the work of Marcel Mauss, she highlights the obligations inherent in the giving and receiving of gifts (Ahmed 2006, 86). As I understand Ahmed, lines can be seen as gifts in Mauss's sense of the term since they offer the recipient a place in the social fabric, an orientation in the world, while simultaneously demanding a return in the form of a reproduction of the line. In discussing lines as gifts, Ahmed uses the very term 'the gift of life' (2006, 86). It is not the gift of an organ that she has in mind here, but the gift of being born in the first place. When a child is born, she argues, the gift of life that this child receives is not unconditional, since the child is expected to extend the line of descent that his or her life itself forms an extension of. In essence, what is demanded is a reproduction of and alignment with a heterosexual orientation (Ahmed 2006, 86). Receiving the gift of life in the context of organ transplantation similarly requires the reproduction of an orientation, what I call the dominant orientation towards transplantation. It was the pressure to reproduce this orientation that Veronica experienced. Since she had received the gift of transplantation, the people around her expected her to exhibit health, normality, and, not least, happiness. But she was unable to fulfil this obligation, which clearly added to the disorientation she experienced in the wake of undergoing the procedure.

Heroic intervention, technological imperative, and freedom

How, then, has the dominant orientation towards transplantation gained so much force and become so widespread? From what sources does it derive power enough, for instance, to shape the information that doctors give and to orient patients and persons in general to expect health, normality, and happiness as self-evident outcomes of the procedure?

Waldby and Mitchell's (2006) discussion of tissue economies in their book of the same name provides a valuable contribution to answering these questions. In the final part of *Tissue Economies* they expose the connections that exist between the 'promise to deliver self-generating bodies at some time in the future' and the 'pressure on "real-time" therapies such as organ transplantation' (Waldby and Mitchell 2006, 162). According to Waldby and Mitchell, in the current absence of any effective genetic therapies capable of regenerating lost bodily functions or defeating death, existing biomedical treatments such as organ transplantation have had to incorporate this promise into their practice. In other words, therapies such as transplantation have been made the real-time proof of the reasonableness of expecting medicine to be capable of creating a completely regenerative body in a not too distant future. The force of the dominant orientation towards transplantation and the promises attached to it thus originate to a large extent from a desire to establish once and for all 'the power of science, technology and medicine to improve the human condition', as Franklin has put it (1997, 203).

Kaufman's (2005) ethnographic study of death and dying in American hospitals also provides valuable insights into the forcefulness and pervasiveness of the dominant orientation towards transplantation. Kaufman argues that there exists a powerful imperative of movement in contemporary medicine, a movement that occurs along two main pathways: 'the heroic intervention pathway' and 'the revolving door pathway' (2005, 85–146). While the latter serves to move patients with incurable ailments out of the hospital, the former welcomes patients into its premises and orients them along lines of intervention that promise the possibility of positive outcomes. According to Kaufman, both pathways function as forceful background logics that neither staff nor patients have reflective access to. She likens them to 'an airport moving walkway – with high sides. Once a patient and a family are placed on one, its logic is more powerful, at least initially, than any individual voice, lay or medical' (Kaufman 2005, 100). Kaufman's pathways are thus similar to Ahmed's lines; they orient the persons who become aligned with them in certain ways and towards certain objects and objectives. As such, the clinical pathways Kaufman describes direct patients and hospital staff towards action, towards doing something and towards aligning themselves with particular norms and values.

There is much to suggest that such pathways are at work also in transplant medicine, and especially so the heroic intervention pathway. Moving along an airport walkway with high sides resembles the experiences of patients who are diagnosed with kidney failure and confronted with the two treatment alternatives, dialysis and transplantation. In being oriented in accordance with the heroic intervention pathway, the two treatment alternatives become charged with diametrically opposing values. Dialysis becomes the 'bad' treatment in that it is devoid of movement. Transplantation, on the other hand, becomes the 'good' or, as we have seen, even the 'miraculous' treatment since it epitomises heroic intervention and forward movement. It becomes the unquestionably desirable treatment, towards which one is self-evidently oriented and from which one expects particular, positive outcomes.

In this context it might even be relevant to speak of the presence of a 'technological imperative', a term that was coined by health economist Victor R. Fuchs (1972) in an essay first published in 1968. According to Fuchs, physicians and health care providers are generally steeped in a tradition that 'emphasizes giving the best care that is technically possible; the only legitimate and explicitly recognized constraint is the state of the art' (1972, 66). This may seem like a rather uncontroversial statement, but when one considers the influence given to technology as a tool for assessing what is the best care, its transformative power comes to light. What Fuchs wants to point out in his essay is that what tends to be considered the best care is generally equated with what is technologically possible at a given moment. One aspect of this dynamic that has been highlighted in the wake of Fuchs's essay is the pressure on health care providers to use and patients to choose a particular technology simply because it exists (Barger-Lux and Heaney 1986, 1314). According to the logic of the technological imperative there can be no valid argument against applying the medical technologies that are considered state-of-the-art. As Koenig puts it, 'Once a new technology is developed, the forces favoring its adoption and continued use as a standard therapy are formidable' (1988, 467). What happens, she argues, is that the technological imperative becomes a moral imperative obliging medical professionals and institutions to provide a particular therapy (Koenig 1988, 486). In light of this, it is not strange that the 'shortage of organs' is generally considered to be the only problem hampering organ transplantation from fulfilling its full lifesaving and normalising potential (Siminoff and Chillag 1999; Sharp 2006; Gunnarson 2012). Since transplantation is currently considered state-of-the-art, states and medical institutions have a moral obligation to provide a sufficient number of organs.

Adding to this is obviously the very content of the promises attached to organ transplantation. In being associated with survival, health, freedom, and a return to a normal life, transplantation is afforded an enormously forceful positive charge. What is promised is to a great degree an alignment with the ideals advanced within neoliberalism. An indication of this was the fact that several of my interviewees described their expectations of transplantation in terms of freedom. Within neoliberal thought, as we saw in chapter 1, freedom is a central concept. It is on the freedom of enterprises and of enterprising individuals that a society is to be founded (see Foucault 2008). As Rose (1999) convincingly illustrates, in such a context there is an intimate intertwinement between freedom and normality. This is so, he argues, because we are 'governed through our freedom' (1999, 62), which means that we are freed from the shackles of the state in a way that makes us responsible for maintaining that freedom by acting as enterprising and self-interested individuals primarily at work with our own self-actualisation. Understood in this way, freedom is both normative and normalising, both an ideal in itself and a means whereby one's alignment with other pervasive ideals may be accomplished. The freedom that the participants in this study expect to regain after transplantation is thus not neutral, but rather inextricably linked to the promise of normality attached to the procedure.

Summary of the chapter

In this chapter I have analysed and explored the participants' way towards patienthood. By means of a distinction between illness and disease, I have described and analysed the complexity that characterises the processes of falling ill and receiving a diagnosis as well as the ambiguous relationship between them. A majority of the participants were diagnosed before they fell ill, and were thereby thrown into a state of uncertainty. Being neither healthy nor ill, or being simultaneously healthy and diseased, disoriented some more than others. While some were able to align themselves quite rapidly with the future-oriented diagnostic line that materialised, thereby avoiding disorientation, others found this more difficult or simply did not find a line to follow. These variations attest to the ambiguous nature of diagnoses themselves. Although their main purpose is to eliminate ambivalence – by categorising, naming, and delimiting bodily dysfunctions and ailments – they are always attached to a person who finds him- or herself in a particular embodied situation, a situation that affects how he or she receives it.

The complexity of this situation, including as it does the person's embodied history and his or her spatiotemporal orientation, also greatly affected how the persons with kidney failure experienced their first encounter with haemodialysis. Despite the attempts of their caregivers to prepare them for the procedure both emotionally and practically, they reacted quite differently to it. Although they often fulfilled the ideal of the participating and prepared patient, many of them experienced their first encounter with haemodialysis as disorienting. This was quite likely due not only to the events that took place during this first encounter, but also to their awareness of the fact that from the point of the haemodialysis initiation onwards they would depend on it for their continued survival.

Here organ transplantation emerged as a solution. In being constituted through a powerful discourse, transplantation was associated with a straightforward return to a healthy and normal life. As a result, a morally and normatively charged line that was possible for persons undergoing haemodialysis to follow took shape. By aligning themselves with this line, prospective kidney recipients thought, they would receive a return in the form of a biomedical procedure capable of bringing them out of patienthood and into a life characterised by a productive and reproductive health and normality. When they actually underwent the procedure, however, a shift in orientation typically took place, through which they realised that organ transplantation was not the self-evident and straightforward normaliser which they had expected. Why, then, I asked, does the highly positively charged and dominant orientation towards transplantation exist? I answered this question by pulling together findings from several researchers, which together illustrated and explained the need for and force of this orientation. Among these were Waldby and Mitchell's (2006) claim that organ transplantation functions as the real-time proof of medicine's miraculous capacities, Kaufman's (2005) contention that there exists a pervasive imperative of movement in medicine, Fuchs's (1972) and others' assertion that medicine is permeated by a technological imperative, and, finally, Rose's (1999) claim that freedom, in neoliberalism, is inextricably intertwined with normality, a contention that led me to conclude that neoliberal ideals are central to the particular values attached to organ transplantation.

4. Three interrelated modes of coping

In this chapter, I explore three interrelated modes of coping that emerge in my empirical material. These are modes of coping that persons with kidney failure employ in order to come to terms, primarily existentially and emotionally, with their embodiment of kidney failure and their dependence on renal replacement therapies in general and haemodialysis in particular. As we shall see, these modes of coping are both deeply entangled with each other and profoundly shaped by contemporary sociocultural processes.

The practical and bodily realisation of the severity of the disease

Although many of the participants in this study found out early on that they had a chronic kidney disease and that their kidneys would inevitably fail, both of which were insights that to some extent prepared them for the entry of renal replacement therapies into their lives, it was when haemodialysis was actually initiated, their accounts indicate, that the impact of the disease on their lives really became graspable (cf. Kierans 2005). It was at this point that their daily life acquired a new rhythm, a rhythm defined by haemodialysis. It was at this point that a new space was added to the spaces of their daily life: the haemodialysis unit. Here, they encountered many new objects and people whom they had to get to know: nurses, doctors, fellow patients, needles, tubes, machines, corridors, and so on. But what happened there did not stay there. It followed them home in the form of fatigue, nausea, hypotension, plasters, medications, and so on.

They also had to become knowledgeably and practically acquainted with their own body in a new way, as an object enacted by the treatment. And, for some, the process of preparing for and waiting for transplantation was initiated.

We are getting somewhat ahead of ourselves here. I will explore in depth what it means to undergo and live with haemodialysis and kidney transplantation in the chapters to come. What I want to focus on here are three interrelated modes of coping that emerge in the participants' stories. These three modes of coping are primarily oriented towards coming to terms existentially and emotionally with the disease and the need for renal replacement therapies. Or expressed differently, these modes of coping constitute three interrelated ways in which the participants endeavour to avoid disorientation by trying to incorporate the disease and treatment into their corporeal schema so that they may live from it rather than towards it, thereby regaining a sense of homelikeness in the world.

As I mentioned in the introductory chapter, and as the previous chapter illustrated, dialysis tends to be the first form of renal replacement therapy that persons with kidney failure encounter when their disease reaches the fifth and final stage. But transplantation is also present early on, in theory as the only alternative to dialysis, and in practice as that which one should direct oneself towards and prepare oneself for. Thus, from an early point in time, persons with kidney failure live with both forms of treatment, and relate to both of them when they utilise the modes of coping that I analyse here. But haemodialysis is ordinarily where they start and what they initially and most actively direct their coping strategies towards.

As I stated above, it is when haemodialysis is initiated that the severity and chronicity of the disease tends to emerge in full force for persons diagnosed with kidney failure, thereby spurring the initiation of the modes of coping mentioned above. This is apparent, for example, in Filips's story. Filips found out that he had glomerulonephritis when he was only sixteen years old. However, this was not the first time he had encountered the disease. His father had also had it, and in 1982, when Filips was only twelve, his father had passed away. For Filips, it took twelve years before he had to undergo haemodialysis for the first time. At this point, taking into account his father's struggles with the disease, kidney failure had been present in his life for a long time, but it was only now that the severity of the condition really dawned on him. When he recounts the events that led up to his having fistula surgery I ask him, 'Did you understand at that point how serious the illness was?' 'I didn't in the beginning,' Filips replies, and continues, 'When they had made the fistula, three to four days passed when I was thinking […] "There's still some hope." And then when dialysis started, I understood that it was [serious].'

That this seriousness is closely linked to the disease's chronicity becomes clear in Marianne's story. As we saw in the previous chapter, Marianne was diagnosed before she fell ill, which meant that she knew she would eventually be in need of haemodialysis. But as it turned out, she had been misdiagnosed, and the treatment had to be initiated acutely and much earlier than expected. This is how she describes the thoughts she had when she was discharged from the hospital after her first encounter with haemodialysis:

> I thought, 'Is this how my life will be, bound to a machine? […] I won't be able to cope with that, to live a life like that.' Because I understood that that was what my life would be like, dependent on a machine. For me that was totally unthinkable…

It is evident that neither the experience of being diagnosed and falling ill with kidney failure nor the information about the severity and chronicity of the disease provided by the caregivers is sufficient for grasping the full seriousness of the disease (cf. Hagen 2013b, 63). Such an understanding can only be achieved through experiencing haemodialysis, an experience that spurs the need, as Marianne's quote illustrates, of finding ways to cope. This is so since one's first encounter with the treatment coincides with one's initiation into its temporal regime, a regime that one has to follow either until one receives a transplant or until the end of one's life.

To broaden our scope a little, in developing therapeutic methods and technologies whereby a growing number of persons may live on despite their embodiment of a chronic and life-threatening disease, contemporary biomedicine creates a need among patients to develop and enact coping strategies. This is work that is performed individually – by the patients themselves; collectively – in patient associations, for example; and professionally – by social workers and nurses, for instance (Franklin 1997; Drakos and Hydén 2011; Mattingly, Grøn, and Meinert 2011). Among the participants in this study, the work performed individually appears to be the most important, at least when it comes to managing the seriousness and chronicity of the disease. But the assistance provided by social workers, nurses, fellow patients, and patient associations is also sometimes mentioned.[44]

Regarding the latter form of assistance, however, there is an asymmetry between the units in Stockholm and the unit in Riga. While the units in Stockholm employ social workers with a counselling function and each patient has a nurse especially responsible for him or her with whom he or she is in regular contact,[45] the unit in Riga has neither.[46] This asymmetry creates different conditions for the development and enactment of coping strategies. But since the most significant work is performed at the individual level, there are many similarities between the two national contexts, as we shall see.

The fact that the coping takes place primarily at the individual level does not mean that it is idiosyncratic. Rather, it is intersubjective in the sense that it can be linked to the cultural processes that have enhanced the individualisation of societies in the wake of the increased implementation of neoliberal policies in recent decades (Harvey 2005; Foucault 2008; Fioretos 2009). In the context of haemodialysis and kidney transplantation care, moreover, the sheer existence of three interrelated modes of coping, identifiable in Latvia as well as in Sweden, indicates that there exist culturally and normatively charged conventions about how a seriously and chronically ill person should cope with his or her disease.

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[44] See Gunnarson (2015) for a thorough analysis of patient interaction in haemodialysis.

[45] Despite the neoliberal reforms that the Swedish health care system has undergone since the early 1990s, there still exists quite an extensive support system around each patient (cf. Harvey 2005, 156).

[46] This is likely to be due to some extent to the economic hardships that Latvia experienced in the wake of the global financial crisis in 2008. But it is also likely due to the neoliberal reforms that have been implemented since the early 1990s, which have led to the privatisation of many social support functions (Tragakes et al. 2008, 52–54). The support is there to be bought, but as chapter 6 will reveal, the majority of the patients at the unit in Riga do not have the financial means to do so.

Before moving on to describe and analyse these three modes of coping thoroughly I would like to present them briefly. I call the first one 'the body without kidneys' since it concerns the process by means of which persons with kidney failure come to embrace the biomedical definition of the disease, causing them to link the existence of the kidneys with their function only. The second mode of coping, 'acceptance', concerns the emphasis kidney failure patients place on the significance of, and struggle to achieve, an acceptance of their predicament. I call the third mode of coping 'thought monitoring' since it concerns the constant work of orienting their thoughts in certain directions that persons with kidney failure are engaged in.

The body without kidneys

Numerous scholars have emphasised and often criticised the way in which biomedicine objectifies and thereby dehumanises the human body (see e.g. Kleinman 1988; Toombs 1992; Sharp 2000). In contemporary biomedical practice, it is argued, the body is standardised and universalised (Lock and Nguyen 2010, 20), fragmented and commodified (Sharp 2000), viewed as a complex system (Martin 1994), given mechanistic and machine-like properties (Scheper-Hughes and Lock 1987), and so on. Within the practice of organ transplantation, striking examples of such objectifications have been identified. 'In order for body parts to be made alienable', write Lock and Nguyen, 'they must first be visualized as thing-like, and detachable from the body, dead or alive' (2010, 244). In the course of recent decades, as 'a metaphor of a "shortage" of organs' has become prevalent within 'transplant discourse', an increasing number of people have begun to advocate a legalised market in organs (Lock and Nguyen 2010, 235). The resulting '"commodification" and "marketification"' of human body parts, according to Fox and Swazey, 'has been accompanied and reinforced by the progressive biologization of donated organs' (1992, 207). 'Increasingly,' they continue, 'organs are being thought of as "just organs",' a development that they argue 'has insidious implications' (Fox and Swazey 1992, 207). As a result of this development, Sharp asserts, 'the heart may be described as a pump, the liver and kidneys as filters' (2000, 304). Elsewhere, Sharp refers to this form of objectification as reification (1995, 377).

Although that term is accurate to some extent, I find the term 'functionalisation' to be better suited to capturing the process of objectification at work when a heart is described as a pump and a kidney is described as a filter. It is important to note, however, that such functionalisation both presupposes and underlies other forms of bodily objectification such as standardisation, fragmentation, and mechanisation.

In the participants' stories the functionalisation of the body in general and the kidneys in particular is salient. This is how Marianne describes the kidneys:

> The kidneys… I mean it's the purification. But the kidneys do a lot of different things, actually. They balance the level of salt in the body, and keep the level of fluid in balance and the blood count as well. When you've gotten to know what the kidney does then you understand its great importance for the body. But since they are so terribly good, of such great importance, we have two. But when the whole renal system breaks down, I mean, then we have none.

In all likelihood, Marianne would not have been able to give me this quite detailed description of the kidneys if she had not been afflicted with kidney failure and undergone renal replacement therapies. Before she was diagnosed with glomerulonephritis, her kidneys were most likely a part of her body that she very rarely, if ever, thematised. According to Leder (1990a), this absence of our inner organs from our attention is due not only to the from–to structure of our bodily engagement with the world, but also to the sheer recessiveness of our viscera, to the unavailability to our consciousness and control of the processes that unfold beneath the surface of our body. But this does not mean, Leder contends, that our viscera are not essential for our sensorimotor engagement with the world. Rather, our being-in-the-world relies on a deep intertwinement between the surface and depth of the body. An example that illustrates this is the experience of hunger. 'Hunger', writes Leder, 'is not just in my stomach but pervades my mouth, my muscles, my mood' (1990a, 51). This is also the case with illness. As the previous chapter revealed, the process of falling ill generally begins as an experience of a shift in the world or in the worldly activities in which we are engaged, even though it is caused by a dysfunction in one of our inner organs. The absence of our inner organs experienced in health is thus due both to their participation in our outward directedness and to their inherent recessiveness. Leder summarises this concisely: 'Each organ both projects outward and recedes inward, eluding the self bidirectionally' (1990a, 56).

But this structure is ordinarily disrupted in illness, and perhaps even more so when an ailment has received a diagnosis and biomedical treatments have been initiated, since diagnoses and treatments tend to highlight and thematise certain body parts in their endeavour to locate and repair or, as in the case of kidney failure, replace a lost function. Throughout the history of modern medicine, new technologies have been invented that not only improve the capacity of medicine to treat various conditions, but also increase its ability to open the inside of the body up for perceptual thematisation. Through various visualising technologies, and by means of machines that emit sound and produce graphs and numbers, medicine opens up the inner depths of the body, not just for itself but also for its patients and the public in general (Foucault 1994; Reiser 2009). This might explain why Marianne, in her account above, is able to recount in such detail the multiple and essential functions of the kidneys. This knowledge is a product of a learning process that probably commenced when she was diagnosed and intensified when she began to undergo haemodialysis.

What I want to get at particularly here, however, is another process that Marianne describes in the quote above, namely the process in which the emergence of the kidneys as dysfunctional, and the gradual or immediate deterioration of their function, coincides with their gradual or immediate disappearance. Marianne says of the kidneys that 'since they are so terribly good, of such great importance, we have two. But when the whole renal system breaks down, I mean, then we have none.' What happens is that, along with the function of the kidneys, go the kidneys themselves. According to this logic, Marianne still had her kidneys when she was diagnosed with glomerulonephritis. But when their function was entirely lost and she had to undergo haemodialysis for the first time, they disappeared.

Marianne is far from alone in referring to her kidneys in this way. My empirical material abounds with such accounts. In describing the events that led up to his undergoing haemodialysis for the first time in 1997, Carlos emphasises the speed with which it all happened. He says, ‘It took two weeks, [then] the kidneys were gone. It just said “shwoop”.’ Although the process went faster for him than for Marianne, Carlos too experienced the loss of the function of the kidneys – materialised as the initiation of haemodialysis – as coinciding with the disappearance of the kidneys themselves. And as the ‘chronic’ in chronic kidney disease indicates, this disappearance is irreversible, and thereby perpetual. Consequently, as a person in need of renal replacement therapies, one has to learn how to ‘to live without kidneys’, as Filips puts it. That such a life is radically different from a life with kidneys is evident in Veronica’s story where she says, ‘It [the kidney] has affected my way of living and my way of being, too. Because without it I’ve had to learn how important it was. [...] My life would have been totally different if it had been with me.’ This statement really illustrates the irony at work here: it is when the kidneys are lost that their significance becomes apparent. Since her first encounter with haemodialysis, Veronica has had to learn that it is because she no longer has her kidneys – since they no longer function – that she has to replace them with a machine and radically alter her entire way of living. However, referring to the kidneys as gone serves to explain not only why they have to be replaced by particular medical interventions, but also why the body acts in a certain way, why one feels a certain way. ‘Without kidneys’, Liouba says, ‘there’s fatigue.’ Stanislav describes it in a similar vein: ‘The absence of kidneys, even of one of them, decreases stamina. If you lack both of your kidneys, you have no stamina at all.’

As these brief excerpts from my interviews suggest, the idea that the loss of the function of the kidneys coincides with the loss of the kidneys themselves is common among my interviewees. It is also evident that they tend to use this idea as a way of explaining and giving meaning to the radical transformations of their body and life that have taken place since they underwent haemodialysis for the first time. Since such a vital organ with so many important functions is gone, it is not strange that the way I experience my body and the way I live my life have changed so radically, they seem to tell me. It is because it fills this explanatory and meaning-giving function that I characterise this idea of the body without kidneys as a coping strategy, even though the participants do not always seem to be aware of using it as such.

It is likely that this unawareness is due partly to the fact that it is not only of their own making. As we saw above, several scholars have accused transplant medicine of biologising and reifying human organs, of viewing hearts merely as pumps and kidneys merely as filters, what I call functionalisation here. Sharp (1995, 2006) has shown how transplant professionals actively pass this understanding of human organs on to their patients before and after transplantation. Their main motivations for doing so, Sharp argues, is to help patients cope with having another person's organ in their body. In advancing the idea that the kidney they have received is merely a filter, the transplant professionals hope to convince their patients that the donor's personality does not accompany the organ into their body – something they not infrequently fail at, not least since, at the other end of the organ transfer chain, intensive care professionals speak of the donor as living on inside the recipient's body.

My empirical material illustrates, however, that persons with kidney failure encounter the functionalisation of their kidneys long before they receive an organ. The kidney is thematised already at the time of diagnosis as something providing the body with a particular and vital function. When haemodialysis is subsequently initiated, this functionalisation intensifies radically. It is when they experience the invasive measures required for replacing the lost function of their kidneys that these two organs emerge as something primarily functional – providing multiple and vital functions – for the participants. As the next couple of chapters will show, haemodialysis extends this orientation towards the kidneys since it requires patients to pay attention to how well the treatment succeeds in replacing these lost functions, and since it compels patients to transform their lives in order to minimise the effect of the treatment's shortcomings on their well-being. The functionalisation of the kidneys is not the patients' own invention; it is intrinsic both to the biomedical definition of the disease (see Levey et al. 2005) and to the treatments associated with it, facts that patients soon learn and eventually grow accustomed to.

But it is the patients, and not the doctors, who make the logical deduction that with the loss of the function of the kidneys, the kidneys themselves go. If the kidney is nothing more and nothing less than an organ providing the body with multiple and vital functions, the participants in this study deduce, then when these functions vanish, so do the kidneys. Rather than experiencing themselves as dehumanised by this objectifying functionalisation, the participants embrace it and go a step further than medicine along this logical chain.

This tells us that objectification is not always dehumanising or, for that matter, to use Ahmed's terminology, disorienting. We have already seen indications of this in the previous chapter when Rune, for example, managed to cope with the emergence of his kidneys as dysfunctional objects by orienting himself in line with the future-oriented diagnostic line that materialised at the time of diagnosis. But this becomes even more evident in the context of the creation and enactment of the body without kidneys. What the participants tell me is that, in the situation they were in when they had lost the function of their kidneys and had recently begun to undergo haemodialysis, objectification did not constitute the primary threat to their feeling of homelikeness. The main threat was posed instead by the tremendous changes to their life and their body that the disease and treatments forced upon them and forced them to make. Here, rather than standing in their way, the objectification of their kidneys emerged as a means whereby they were able to explain and give meaning to their predicament. They became able to 'manifest agency (and so enact their subjectivity) through their objectification', as Thompson expresses it (2005, 179).

In her ethnographic study of reproductive technologies, Thompson found that objectification, in some situations, aligns with or even facilitates the 'trail' of 'the long-range subject' – that is, the patient's desired orientation – and is thereby not experienced as dehumanising (2005, 203). As Zeiler (2010) points out, what matters is not whether or not a person experiences his or her body as an object; what matters is whether or not the objectification disrupts his or her intentions. For the participants in this study, it did not. Their encounter with their functionalised kidneys and their enactment of the body without them – at the time of the initiation of haemodialysis – did not disrupt their intention to avoid disorientation in the face of the radical transformation of their body and life that they experienced. Rather, it helped them.

These findings indicate that it is necessary to question, as Weiss (1999) and Thompson (2005), among others, have done before me (see also Kierans 2005; Lock and Nguyen 2010, 244; Lundin 2012b), 'the long tradition that sees objectification as alienating and that sees technology as always in imminent danger of usurping selfhood' (Thompson 2005, 180). Objectification can be dehumanising and detrimental to the self, as Weiss and Thompson both point out, but it is not always so. The task of research is therefore to conduct an analysis that is sensitive to the contextual and situational circumstances that influence how objectification affects a person and how a person may affect and act upon objectification, a task that I carry with me throughout this book. In the particular situation explored here, objectification materialised as one of three interrelated modes coping by means of which the participants attempted to avoid disorientation and regain a homelike being-in-the-world after starting haemodialysis. What this particular mode of coping – 'the body without kidneys' – does that the other two do not is to provide a logical explanation for the need for invasive medical therapies: 'Since the kidneys are gone it's not strange that they have to be replaced by something else.' Next, I turn to the second mode of coping, which I call 'acceptance'.

Acceptance

In their stories, the persons with kidney failure whom I have interviewed return repeatedly to the fact that they have no choice. They have to alter their lives to accommodate haemodialysis, because if they do not – nurses and doctors tell them – they will die (cf. Russ, Shim, and Kaufman 2005, 304). If there is a choice, it is that between life and death. But few regard this as a choice at all. Tomas is one of the few who do. He says:

> You just have to grin and bear it. If I don't come here [to the haemodialysis unit], I die. That's how it is. You just have to choose what you want to do. And it's totally voluntary to come here […]. No one can force me to come here.

Tomas clearly considers there to be a choice between death and a life with haemodialysis. But it is not a choice that is easy to face; it is something you have to 'grin and bear'. As a person with kidney failure, Tomas seems to say, you are constantly living with the alternative of going or not going to the treatment unit – of living or dying – and this is a fact you have to grin and bear. Or, expressed differently, in order to live with haemodialysis you have to accept the fact that you are in a situation where the choice between life and death is always present.

But as I mentioned above, a majority of the participants do not view this as a choice at all. This is most often not expressed explicitly but rather implied in an emphasis on the absence of choice. This is how Indra describes it: 'At first I thought it [her dependence on haemodialysis] was awful, but now both of us [she and her husband] have accepted this fact and, after all, we've found solutions. I have accepted that I don't have any other option.' In this quote the choice between life and death, made explicit by Tomas, is absent. Choosing life, it seems, is considered so self-evident that it is not perceived as a question of choice. This also applies to me, since I never followed up such statements with a question about the possibility of ending therapy. Life as the only possible option was evidently a notion that our conversations often implicitly presupposed. It is this shared conviction that makes it possible for Carlos to refer to the entire human race when he says, 'It's built into the human being that you want to live as long as possible. You don't want to die.'

But to go on living, persons with kidney failure have to radically alter their lives. Into the life that was up until recently led, a time-consuming and exhausting medical treatment regime must be integrated, a regime that can only be avoided by waiting patiently for a kidney from a deceased donor or by asking a relative or a friend to donate. Moreover, since there is no choice but to choose life, according to the participants, there is no choice but to submit oneself to these drastic changes. This is not only a practical matter; it is not just a question of doing things differently. As was evident in Indra's words above, it is also an existential matter; something that one has to cope with intellectually and emotionally, something that one has to try to accept. These practical and existential dimensions are inextricably intertwined, as the proximity of the word 'accept' and the phrase 'we've found solutions' in Indra's account indicates. While there is a tilt towards the existential in the exploration of the three interrelated modes of coping that I conduct here, the practical dimension will receive extensive attention in the chapters to come.

According to Anthony Giddens, in 'high modernity' we are confronted with 'a complex diversity of choice' and are responsible for conducting our own 'colonisation of the future' (1991, 80, 86). In order to create and steer our lives along a 'reflexively organised trajectory of the self' we need to make 'lifestyle choices' and engage in 'life planning' (Giddens 1991, 85). This does not mean, he argues, that we have ceased to be fatalistic. Fatalism, defined as a 'resigned acceptance that events should be allowed to take their course', is an important aspect of our time (Giddens 1991, 112). Even though they run counter to each other, fatalism and the colonisation of the future are both, Giddens contends, products of the 'secular risk culture' that we now find ourselves immersed in (1991, 131). Fatalism and the colonisation of the future are two opposed ways of approaching the risks that this culture produces. The fatalistic approach, which is the focus of my interest here, is ordinarily utilised when a perceived risk lies outside individual or collective control, Giddens argues. On such occasions 'we might as well decide that "whatever will be will be"', he writes (Giddens 1991, 131).

Notably, while Giddens discusses how the colonisation of the future relates to both choice and risk, he mentions fatalism only in relation to risk. But I believe that it is possible to infer from his analysis that not only is fatalism intimately linked to choice, but choice is also intimately linked to risk. While the colonisation of the future is founded on the idea that choice is what enables an individual to simultaneously shape a desired future and avoid future risk, fatalism is a response to situations in which there are no or very few alternatives to choose from or in which faith in the ability of choice to shape a desired and risk-free future is low or has been completely lost. The colonisation of the future and fatalism are thus opposed in the way they relate to choice and risk. But as two responses that have to be reflectively and practically achieved, they are similar. Fatalism, as much as the colonisation of the future, is a reflexive project, something that has to be cultivated.

This is akin to what Hamdy (2009) found in her study of Islam and kidney transplantation. Although Hamdy writes about the cultivation of an ‘acceptance of divine will’, her findings are relevant also in the context of a secular risk culture (2009, 174). Like Giddens, Hamdy addresses the significance of a loss of control for the adoption of a fatalistic approach, but she brings choice more explicitly into the equation. During her fieldwork at a haemodialysis unit in Egypt Hamdy noted how the patients, in their encounter with haemodialysis and transplantation and in the face of the loss of choice and control that this entailed, had to ‘actively work upon their selves to cultivate dispositions of acceptance to God’s will’ (2009, 177). Acceptance could never be settled once and for all. Instead, Hamdy writes, ‘Every day posed challenges, and it continued to be difficult to get from one day to the next’ (2009, 180). Therefore, she concludes, fatalism is neither unchanging nor passively attained; it has to be actively cultivated. Quite paradoxically, in the sense of being something that is achieved by a person who responsibly and autonomously responds to a particular situation, fatalism aligns itself with ideals found in neoliberalism; but in constituting a refutation of individual choice, it does not. Consequently, when persons with kidney failure come to need renal replacement therapy they are thrown into a situation to which they have to respond responsibly and autonomously but in which the alternatives at hand are severely limited (cf. Mol 2008).

In my empirical material, direct references to fatalism are few. They occur only in my interviews with Boris and Rune. While Boris refers to himself as a fatalist throughout the entire interview, Rune uses the term only once to describe his relation to the haemodialysis machine. Even so, I find Giddens’s and Hamdy’s theorising around fatalism useful for my purposes here since, in their understanding of the concept, acceptance plays a crucial role. But instead of an acceptance of God’s will, which Hamdy’s informants struggle to achieve, most of the participants in this study cultivate a secular acceptance of the medical explanation of their predicament, an explanation that tells them that they embody a disease which is fatal if it is not treated with dialysis or transplantation. This attests to the deep intertwinement between disease and treatment, an intertwinement that becomes even deeper when haemodialysis is initiated. The question then arises what exactly it is that persons with kidney failure have accepted when they tell me they have achieved an acceptance of their predicament.

If we return to Indra's account above we can note that she uses the word 'accept' on two occasions. On both occasions her acceptance is directed towards her dependence on haemodialysis. First she states that she and her husband have accepted the fact that she is dependent on haemodialysis. Then she asserts that she has accepted that she has no other option but to undergo haemodialysis. The latter of these two assertions is particularly revealing for our purposes here since the absence of options that Indra refers to, and which she has accepted, is tightly linked to the medical conceptualisation of the disease as a life-threatening and chronic condition. What Indra accepts, then, is not only her dependence on haemodialysis, but also her embodiment of a life-threatening and chronic disease, which is what deprives her of her options. What transpires here can be summarised as follows: along with the kidneys goes choice. When the kidneys disappear so too do one's options. This shows the deep interrelatedness of the two modes of coping analysed so far. On the one hand, it is by accepting the medical conceptualisation of the disease that the logical inference that the kidneys are gone can be achieved. On the other hand, it is the loss of the kidneys that explains the loss of choice, which makes it sensible, if not necessary, to accept one's dependence on haemodialysis. What Indra accepts when she accepts the absence of choice is thus both her embodiment of the disease, in the form it takes after the treatment has been initiated, and her dependence on the treatment. But as we saw above, this acceptance is intimately linked to the way in which Indra and her husband have adapted themselves to the treatment practically. But more about this later. I wish now to turn to the question why the participants consider it important, if not necessary, to achieve an acceptance of their predicament.

Why accept?

At the point in our conversation when Rune describes how he relates to the haemodialysis technologies, he comes to the conclusion that 'it's important for all dialysis patients and everyone in a similar situation to accept things as they are, because if you don't, it will affect other parts of your life as well'. Rune does not elaborate further on how and what other parts of life become affected when one does not accept. In this respect, Marianne's story is enlightening. In the beginning, before she accepted that she had no option but to undergo haemodialysis, Marianne thought life was unfair. Why had she been afflicted? she thought. But after a few months she began to reach acceptance, an acceptance that has enabled her to think, '"I also have a life, and it turned out like this." I mean, you can't fight back, fight back, fight back, because, I mean, then you go mad. You just have to say, "Yes, this is how it is, these are my frames, they are pretty narrow but…".'

From what Marianne says here, we may learn that the reason a failure to accept affects 'other parts of your life as well', as Rune puts it, is that one's life as a whole is deeply implicated in the disease and treatment. What Marianne after a while accepted was not the disease and treatment per se, but her life with them. When she entered the haemodialysis regime, her life as a whole was woven tightly into the intertwinement of disease and treatment.[47] This means that an acceptance of the disease and treatment is also an acceptance of one's radically altered life with them. If this is the case, we begin to see the scope of what is at stake here. But we only understand *that* it is important to accept, not *why* one should do so. This becomes clear if we turn the equation on its head and look at it not from the point of view of disease and treatment but from the point of view of the sick person's life in general. Then we see that an acceptance of a life with kidney failure and haemodialysis hinges on an acceptance of the medical conceptualisation of the disease. If one does not accept that the disease is life-threatening and chronic, why should one accept a life radically altered by the treatment for it? Thus, if one has accepted the fact that one will die if one does not undergo treatment, struggling against the life one's dependence on it creates is futile.

To actually achieve such acceptance is much less straightforward than this explanation might suggest. For Marianne it took months. She underwent haemodialysis for the first time in the fall and in the spring that followed she and her husband went to their cottage in the countryside. 'And then,' Marianne says, 'then, he [her husband] remembers that, after we had been there for some time, it was like I began to see a future, became

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[47] This was so, of course, for Indra as well, although it was not as clear in the quote cited in the beginning of this chapter.

able to look ahead.' What made this change possible is difficult to discern from my conversation with Marianne. But it is reasonable to believe that the sheer time that separated the initiation of haemodialysis from her trip to the countryside was one important factor. In all probability, with time, the importance of which I will discuss more below, undergoing haemodialysis became for Marianne, at least to some extent, a habitual routine, the importance of which I will discuss in the next chapter.

In her ethnographic research on chronic illness Charmaz (1991) distinguishes between acceptance and reconcilement. While the latter denotes the chronically ill person's adjustment to the character of the illness and the way it affects his or her life in the present, the former 'shapes the future as well as the present', Charmaz writes (1991, 48). This temporal character of acceptance was apparent in Marianne's words above. When she began to achieve acceptance, she 'began to see a future' take shape. To use Ahmed's terminology, Marianne began to reorient herself. To be oriented, as I wrote in chapter 2, is not only to be directed from an embodied past, but also to be directed towards the future (Ahmed 2006, 21). As we shall see in chapter 6, for persons with kidney failure this future-orientedness is not a colonisation of the future in Giddens's sense of the term, involving long-term life planning, but rather the achievement of a sense that a life with the disease and the treatments can be possible, combined with short-term work on one's body and self to create a functioning everyday life.

Medicine itself also plays a part in this future-orientedness, not least through its imperative of movement (Kaufman 2005). As Kaufman contends, the imperative of movement in medicine functions as a forceful background logic to which neither staff nor patients have reflective access. I would argue, however, that its function as such a background logic hinges on the acceptance by the involved actors of the biomedical model of explanation for the disease and the need for certain therapeutic interventions. When such an acceptance has been achieved, medicine can begin to assist in the sick person's future-orientedness. Dmitry describes this almost poetically: 'It's like a stream holds you. You are taken by the stream and the current takes you through life with all the diseases, check-ups, transplantations, and dialysis.'

This is akin to how the women in Franklin's (1997) influential study

Embodied Progress: A Cultural Account of Assisted Conception described their experience of undergoing assisted reproduction therapy. When they started the treatment, it was as if it completely took over and became 'a way of life' (Franklin 1997, 131). This attests to the power of medicine to reshape patients' lives, and to the imperative of movement built into its practice. The idea that something can always be done, be improved, is ubiquitous in contemporary medical practice, even if the chances of a successful outcome are minimal, a fact both Kaufman's and Franklin's studies illustrate. As we shall see in the coming chapters, participating in this imperative of movement by working on their body and self constitutes one of the ways in which chronically ill persons may come to achieve a future-orientedness in the sense mentioned above.

As the discussion so far has implied, there is ordinarily a preferred end point, a goal, built into the imperative of movement in medicine. While in reproductive medicine the ultimate goal is the birth of a child, 'a take-home baby', as the women in Franklin's study call it (1997, 94), the ultimate goal in renal medicine is the successful transplantation of a functioning kidney (cf. Kierans 2005). But as chapter 7 will reveal, the vast majority of the participants in this study, for a variety of reasons, find it virtually impossible to actively strive towards this goal. Reaching it is out of their control, they tell me, which is something that they have to accept, and which, in turn, forces them to accept a life with haemodialysis.

Under some conditions, however, one's path towards transplantation can seem straightforward. This might be the case, for example, when a close relative has volunteered to donate and successfully gone through the screening procedure. This was the case for Carlos. He was not worried when, after living with his transplant for thirteen years, it slowly ceased to function. He knew that he would be transplanted again with his sister's kidney. His sister had already undergone the screening procedure and had been deemed an eligible donor, provided that Carlos, before the operation, underwent a so-called plasmapheresis treatment. The purpose of the plasmapheresis was to rid Carlos's blood of the antibodies that his body had produced during his first transplant. This way, his sister's kidney would not be acutely rejected by his body following the procedure. Prior to the plasmapheresis treatment the doctors had confidently told Carlos, 'We're going to wash them [the antibodies] away.' So, he tells me, 'I thought, "It's going to be all right".' But the treatment was unsuccessful, and the day before the transplant procedure was scheduled to take place the doctors told Carlos that it was not safe to transplant him with his sister's kidney.

Thus, after thirteen years, Carlos had to return to haemodialysis. This was terrible news for him. He was thrown down a black hole. 'What do I do now?' he asked himself. Living with haemodialysis was inconceivable to him, even to the extent that he considered taking his life. But on an impulse, Carlos went over and talked with the patient in the room next to his. He heard a voice in his head, he tells me, that told him to seek out this woman. So he did, and by telling Carlos about her life with self-care haemodialysis she managed to convince him of the possibility of living a good life with this form of treatment. So Carlos concluded, 'I have to change my attitude. Now only dialysis remains, so now I have to accept that and face up to that.'

This eventful and emotional episode attests to the 'erratic character of disease', as Annemarie Mol has called it (2008, 27).[48] In referring to disease as erratic, Mol wants to get at the uncertainty inherent in every medical intervention. Since diseases are erratic, she argues, medicine can never guarantee that a particular outcome will result from a particular intervention. In her writings, Mol does not distinguish between illness and disease (see also Mol 2002). This is unfortunate since it prevents her from seeing that the erraticism she writes about always emerges in relation to something and for someone. Mol's examples of the erratic character of disease illustrate the often-unexpected reactions of the body to the medical measures taken to treat it, but as we shall see in the chapters to come, erraticism can also occur in relation to the experience of illness or in relation to a habituated and incorporated synthesis of illness and disease. We are now, once again, getting ahead of ourselves. What I want to emphasise here, and what my empirical material shows, is that it is often the body, not the disease, that is experienced as erratic; and in such moments, the bodily erraticism always occurs in relation to something – illness or disease, or both – and for someone – a patient or a medical professional, or both.

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[48] Cf. sociologist Arthur W. Frank's (1995) discussion of the body as contingent.

Consequently, when I write about erraticism I use the term 'the erratic body' rather than, as Mol does, 'the erratic character of disease'.

In the episode recounted above, Carlos's body emerged as erratic, at least for him, but, as it seems, also for his caregivers. Suddenly, on the day before transplantation, his body turned up as something that had not reacted to treatment as expected and therefore would not react well to transplantation. This shows us that the emergence of the erratic body often coincides with the alienating effect of the dys-appearance of the body. In this particular situation, the erratic body, materialised in the form of the dys-appearing body, stood in the way of the embodied orientation towards transplantation that Carlos had taken, and appeared as something with a will of its own, as something disrupting his intentions. This disoriented Carlos, deeply. He realised that in order to survive he had to reorient his life completely, and align himself with a life on haemodialysis, which, to him, was virtually inconceivable. But only a short time later, through the encounter with a fellow patient, his reorientation began. Here, his acceptance played a crucial role: 'Now only dialysis remains, so now I have to accept that and face up to that,' he thought.

It is clear that the ubiquitous potential emergence of the erratic body, or, put in simpler terms, the inherent bodily uncertainty with which chronically ill persons live, is one of the reasons acceptance has to be cultivated. When one lives with a chronic disease there is always the risk, or chance, that one's body will suddenly emerge in a way that requires a radical reorientation of one's self and one's life. In time, however, the erraticism of the body can become something that one is able to include in one's considerations. The erratic body may then itself become an object of acceptance.

This is evident in another quote in which Carlos discusses the new way of thinking he has acquired since he fell ill. He says, 'I feel that there's no such thing as "that's how it is". Life changes all the time. For example, today it's cloudy and tomorrow it's sunny. But it's like that [with my illness as well], today I feel well and, perhaps, tomorrow I feel worse…' Carlos is constantly aware of the erraticism of his body. Regardless of whether he follows all of his medical prescriptions and whether he adapts his life to accommodate his illness, he has little control over his body. He does not know from one day to the next how he will feel. But just as he has accepted that he cannot control the weather, he has accepted that he cannot fully control his body. He has to some extent come to terms with the erraticism of his body.

How does one accept?

Here the question arises: exactly how does one accept? Or rather, what circumstances favour the achievement of acceptance? The fact that there was a patient with extensive experience of living with haemodialysis in the room next to Carlos's was essential for his achievement of an acceptance of his new situation. For Veronica and, as we saw above, for Marianne it took time. 'There's a long time when you're angry and you don't want it, and it takes many years before you accept it in a way, or adapt to the situation,' Veronica says. The reason it took such a long time, Veronica tells me, was that she needed to get over her fears. In the beginning it was not only undergoing haemodialysis that scared her; she also found doing the chores in her home frightening. She was afraid that carrying out some of the actions she had previously considered mundane could worsen her condition. 'Then you limit yourself more than you need to because you're so scared,' she tells me. 'But then, with time, you learn that "No, it works." You try and it works.' In Veronica's case, then, making it work was intimately connected to achieving acceptance, which once again attests to the deep intertwinement between the practical and the emotional – and more generally the existential – that often characterises the quest to achieve acceptance. Veronica's acceptance of the treatment hinged, to an equal extent, on her ability to come to terms with the practical and the emotional. Here, time was an essential ingredient. Time was needed for her to emotionally and practically adapt to her new life with the treatment.

But time is important also in another sense, namely in the sense of the timing of the onset of the illness. Veronica hints in passing that this was important for her as well. She says, 'Maybe it would have been easier if I'd been older when I fell ill.' When her illness broke out, she was in her forties and was at the time just about to start a new job. Thus, the timing was bad and made it difficult for her to achieve acceptance. This can be contrasted to the role of timing in Indra's story. When Indra's kidneys failed and she became dependent on haemodialysis, she soon found out that she was not eligible for transplantation. This, she was told, was due to her old age in combination with a whole range of other contraindications – asthma, heart problems, and diabetes, for instance. The timing of her illness, materialised in the form of old age, was thus one of the doctors' motives for not admitting her to the waiting list for transplantation. This made it possible for her to use age as an explanatory model for her acceptance of her situation. 'I have to accept,' she says. 'Age does not come alone. I can't expect myself to be young and have all the chances. My old years are here and that's it.' The idea that with old age one has to acquire new, or perhaps do away with some old, expectations is widespread among the participants in this study. Indra clearly shares this notion, and her conviction of the need to accept her situation is reinforced by it.

But Indra's religious beliefs also play an important role. When I ask her how she feels about knowing that she will be required to undergo haemodialysis for the rest of her life, she replies, 'As I said, I've accepted that. I'll live as long as God wills. It's the same as having diabetes for twenty years – all you can do is accept.' If the illness is prescribed by God, then there is no other option but to accept it, Indra seems to say here. Liouba, on the other hand, feels that God, by making her fall ill, has tested her. Her task, therefore, becomes to live with the illness in a way that lives up to God's expectations.

As Hamdy (2009) so eloquently shows, the acceptance of a divine will may not be so easily achieved and has to be continually cultivated. This is evident in Filips's story. Filips has had three transplantations, none of which has been particularly successful. When we discuss how long he would have hoped it to work, he smiles ironically and says, 'As long as God wills. But it was hard somehow… I understood that for some it works for a long time, for five to six years, and for others, ten years and more. I was thinking… "It will be as it will be."' In both of our conversations, Filips tells me about his faith, which, he says, has become stronger since he fell ill. Yet when his first transplant was rejected after only three years, his acceptance of the will of the divine was put to the test. 'It was hard somehow,' he says, referring, I believe, to achieving an acceptance of God's will. This prompted him to take some time to think before arriving at the conclusion that 'it will be as it will be'. Thus, the experience of organ rejection clearly required Filips to work on himself, to cultivate a new acceptance.[49]

I would like, finally, to revisit the personal and experiential conditions that Hans referred to when he described his first encounter with haemodialysis in the previous chapter. According to Hans, his experiences prior to falling ill had afforded him personal qualities enabling him to quite quickly accept the radical changes that becoming dependent on haemodialysis entailed. Yevgeniy also emphasises the significance of his personality for his ability to accept a life with renal replacement therapies, but he does not refer to his previous experiences. 'I'm really not the kind of person who sits and thinks a lot and picks myself apart from the inside,' he tells me, 'especially when I cannot influence the situation. The situation is as it is, and that's all! You should accept this and continue to live under these circumstances.' This statement brings us to the next coping strategy. In emphasising the importance of monitoring one's thoughts, of not thinking, for achieving acceptance, Yevgeniy demonstrates the intimate interrelatedness between 'acceptance' and 'thought monitoring', which I turn to next.

Thought monitoring

As Yevgeniy's words above indicate, achieving acceptance hinges to some extent on one's ability to monitor one's thoughts. But the reverse is also true: when one has accepted the absence of choice and control, monitoring one's thoughts becomes easier. When I meet Yevgeniy for the first time in the fall of 2009, he is hoping to get admitted to the waiting list again, after having been transplanted on two occasions already. So I ask him how he will manage waiting for a third kidney. 'In no way,' he says. 'I'll have dialysis, that's all. Nothing will change. Nothing depends on me. I can't make the process go faster. [I can't] affect the situation. So there's no sense in thinking about it.' It is interesting to note here that, from my perspective

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[49] References to religious beliefs, like those above, are much more common among the Latvian participants. Clearly, my empirical material mirrors the fact that Latvia is a more religious country than Sweden (see http://ec.europa.eu/public_opinion/archives/ebs/ebs_341_en.pdf, accessed 2015-09-30).

as an outsider, I view Yevgeniy's admittance to the waiting list as an essential and transformative event. When he starts waiting for his third transplant, a new situation will arise, I seem to imply. But Yevgeniy immediately rejects this idea. 'Nothing will change,' he tells me. He will face the same absence of choice and control as he did when he first entered the haemodialysis regime, he seems to say, and this is something he has accepted. So thinking about it is senseless. This tells us that one's achievement of acceptance is not only the result of one's avoidance of certain thoughts, but is also a prerequisite for one's realisation that thinking certain thoughts – that pondering the circumstances of one's situation – is futile and meaningless.

But it is not only futile and meaningless. It may also be directly harmful, causing an unhomelike being-in-the-world in the form of, for example, depression. 'I don't think about the disease too much,' Lidija tells me. 'There are people who think, [and they] wallow in depression. This was the case for me this summer, when that kidney [her second transplant] didn't work. I was depressed a bit. But then I thought, "Why torture myself?"' Dwelling on a failed transplant and the erratic reaction of one's body to a carefully planned medical procedure may have severe consequences. In describing it as a form of self-torture, Lidija makes herself responsible for avoiding such consequences, for avoiding brooding and, by extension, depression. This is the general impression I get from all of the participants, Latvian and Swedish alike: the responsibility for avoiding meaningless and harmful thoughts lies with them as individuals. But at the units in Stockholm, patients may seek professional assistance in carrying out this work, and they sometimes do. Further, as Lidija's words indicate, this work of thought monitoring is never completed. Due to the erraticism of the body, things may suddenly change, altering the bodily foundation from which one's thoughts were previously directed. Thus it is possible to contend that, just as one constantly has to cultivate acceptance, one has to cultivate a way of thinking, or a way of monitoring one's thinking.

This need for cultivation is not due only to sudden and surprising bodily dys-appearances. Being chronically ill often also entails witnessing the gradual deterioration of one's body, a process that many of the participants in this study also try to avoid thinking about. At the age of thirty-two Stanislav is already witnessing the slow deterioration of his body. After four years on haemodialysis, he has lost feeling in his arm. But, he says, 'In general I try not to think about things like that, such as my vision getting worse and that I'm losing hair. [I try] not to trouble myself.' Since his body is constantly changing, or, rather, deteriorating, he has to relentlessly create new ways of directing his thoughts elsewhere. This is not easy. 'I try,' Stanislav says, implying that he does not always succeed. As Leder shows, instances of dys-appearance exert an 'existential demand' on us to thematise our body (1990a, 92). Consequently, it takes work to incorporate and successfully orient one's attention from rather than towards one's altered body.

It is not only present but also past and future events – as we saw in Yevgeniy's account above – that are drawn into this work. Marianne, who was initially misdiagnosed, believes that if her vasculitis had been detected at the outset, she would probably not have had to start dialysis until the time of our interview in 2010. 'And that's a bit sad when you think about it. You shouldn't think about it so much,' she says. There is force in these words. Of course one should not dwell on a mistake that was made twenty-five years ago. But this particular mistake had unimaginable consequences; it changed Marianne's life forever. It is not difficult to understand why this is difficult to avoid thinking about and requires Marianne's active monitoring of her own thoughts. Many of the participants are struggling with difficult experiences from their past. Dmitry, for instance, tells me that all the scars on his body remind him of the difficult surgeries he has been through. But 'I don't dwell on it,' he says. 'I have enough other problems.' Here, and in Yevgeniy's account above, it seems that concentrating on the demands posed by a life with haemodialysis in the present and accepting the absence of choice and control that to a large extent characterises one's present situation may make it less difficult to avoid thinking about the unpleasantness of the past and the uncertainty of the future.

This brings us to the most common method the participants use to avoid thinking certain thoughts: activity. To avoid 'pessimistic thoughts', as he terms them, Ivan keeps himself occupied by repairing cars or going out for walks or drinks with his friends. Veronica also emphasises the importance of being around other people. This prevents her from engaging in too much introspection, she says. Stanislav, on the other hand, prefers the solitary activity of reading books. He says that this helps him ‘switch to something else’. Camilla tries to be active in general. She says that she would probably go mad if, despite her dependence on haemodialysis, she did not live an active life. But she also emphasises the importance of the haemodialysis nurses who ‘get you going again, so you don’t just sit there and get stuck…’ Dmitry, on the other hand, has no choice but to be active, he tells me. With a thirteen-year-old son to raise and a job doing computer diagnostics for cars, ‘you have no time to think’, he says.

Viewed from a purely phenomenological perspective, this link between activity and the absence of thoughts about one’s bodily state is quite self-evident. As Leder points out, when we are engaged practically in the world, we tend to be oriented from rather than towards our body (Leder 1990a). We do not interact very well with other people, which is what Ivan and Veronica prefer to do, or read books very well, which is what Stanislav likes to do, if we are constantly thematising our body when we engage in such activities. This does not mean that the emphasis that these participants put on the significance of being active is normatively and morally neutral. As Rose points out, neoliberalism advances a forceful and particular ‘imperative of activity’ (1999, 268). What sets this activity ideal apart from earlier versions of it is the form of activity it prescribes. In the neoliberal context it is not enough to be active in general, to engage in activities of just any kind. Rather, Rose writes, one should be ‘active in [one’s] own government’ (1999, 142). In other words, one should be autonomously and responsibly active in making choices oriented towards one’s own and one’s family’s future. Consequently, activity becomes intimately linked with freedom, since, within neoliberalism, individual freedom hinges on a person’s ‘capacity for self-realization which can be obtained only through individual activity’ (1999, 145).

With this in mind, it is quite unlikely that Ivan, Veronica, Dmitry, and Stanislav would be considered active when they engage in the activities they do in order to avoid negative thoughts. Since the purpose of their activities is self-preservation more than self-realisation, their actions are most likely not oriented enough towards particular, individually created goals to be considered examples of proper neoliberal activity. Yet their emphasis on the significance of being active for avoiding certain thoughts would not be understood completely if the existence of this imperative of activity were not taken into account. In linking activity with normality, this forceful imperative turns it into a desirable feature to attach to one's personality, a linkage that Ivan, Veronica, Dmitry, and Stanislav are anxious to achieve.

The normative charge of thought monitoring

The very activity of thought monitoring that the participants engage in is highly normatively charged. In monitoring their thoughts, they engage in an activity that, in a neoliberal context, is often considered necessary for a person's self-realisation (Binkley 2011). In this context, however, one is not entirely free to determine the content of one's thoughts. One should, for example, think positively rather than negatively. As several scholars have pointed out, just as there exists an imperative of activity, there exists today a forceful imperative of positivity (see Ehrenreich 2009; Ahmed 2010; Binkley 2011). In her fascinating book *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America*, Barbara Ehrenreich (2009) traces the historical roots of this imperative to nineteenth-century Calvinist Protestantism. But it was not until the late twentieth century, she argues, through the onset of 'consumer capitalism', that it became an essential constituent of the ideology with which 'we explain the world and think we ought to function within it' (Ehrenreich 2009, 4, 8). As such, the imperative of positivity, just like the imperative of activity, is productive of the 'autonomous, agentive neoliberal subjectivities' idealised today, subjectivities that govern themselves not only through their activities, but also through monitoring their thoughts (Binkley 2011, 372).

When the term positive thinking is used, Ehrenreich argues, it ordinarily denotes both the 'positive thought itself' and the 'practice' of thinking positively (2009, 5). She defines the former as a future-oriented thought expressing the conviction that all is going to be well, and the latter as a practice based on the promise that an optimistic state of mind will make 'happy outcomes more likely' (Ehrenreich 2009, 5). Here we see the link between positive thinking and happiness, a link that has recently gained scientific legitimacy through the new academic discipline of 'positive psychology' (Binkley 2011). Through this linkage, and in this academic discipline, Ahmed argues, happiness is correlated with optimism, creating an equation in which 'happiness becomes its own cause' (2010, 9). As a result, if a person is not already happy, the promise of happiness is to be found in acquiring a positive way of thinking. Inherent in this correlation and essential to the imperative of positivity, therefore, is the idea that we may affect processes that seem to be out of our control merely by thinking in a certain way. An example of this is the presence of the ideal of positive thinking among sufferers of various diseases. Ehrenreich's example is cancer, and more specifically breast cancer, which she herself has suffered from. 'Eight years later,' she writes, 'it remains almost axiomatic, within the breast cancer culture, that survival hinges on "attitude"' (Ehrenreich 2009, 33; see also Wilkinson and Kitzinger 2000). Thus, according to the imperative of positivity, positive thinking may not only cause happiness, but may also enable a person to defeat a life-threatening disease.

Given its close association with consumer capitalism and neoliberalism, one easily gets the impression that positive thinking is entirely a 'Western' phenomenon. But it is not. It was, for instance, an essential feature of the Communist regime in the Soviet Union. According to Pekka Pesonen (2005), Soviet rule was characterised by a 'historical optimism' that saw history as an inevitable development towards 'a bright and better future'. 'Utopia was the truth,' he writes, and 'being charged with a lack of historical optimism meant being charged with distortion of the truth or transmission of false truths' (Pesonen 2005, 15). As Dubravka Ugresic (2003) points out, during Stalinist rule being accused of 'defeatism' could result in one's incarceration in a Stalinist labour camp. Much has changed since the fall of the Soviet empire, but according to Ugresic, 'If anything has survived Stalinism itself, it is the Stalinist demand for optimism' (2003, 86; see also McKevitt, Luse, and Wolfe 2003). Thus, quite paradoxically, the historical optimism of Communism fits hand in glove with the positive thinking of late, neoliberal capitalism.

In creating a link between positive thinking and happiness, the imperative of positivity also links negative thinking and unhappiness (Ehrenreich 2009; Binkley 2011). Just as positive thoughts create positive outcomes, negative thoughts are said to create negative outcomes. Further, according to this logic, it is not only negative thoughts per se that should be avoided, but also what positive psychologists call 'rumination', that is, the activity of engaging in too much thinking, of 'overthinking' things (Binkley 2011, 389). Here, the solution is presented in the form of activity. By being active, it is argued, one may avoid the destructive effects of thinking too much (Binkley 2011, 389).

This echoes the words of the participants in this study. In describing how they actively monitor their thoughts and try to activate themselves, they align themselves with the pervasive lines of the imperative of positivity. But is it unequivocally so? No, not completely. I do not believe that in avoiding thoughts that make them feel bad, or even ill, the participants necessarily embrace the idea that the thoughts they think will have a direct effect on their future. Rather, the absence of choice and control that they experience in the present tends to orient them to regard thoughts about the future as meaningless or even harmful. What I do believe, however, is that the imperative of positivity, and the neoliberal processes of responsibilisation and autonomisation on which it relies, is a factor that motivates them to perform the thought-monitoring work they do and provides a context in which such work is perceived as normal.

The presence of the imperative of positivity in the lives of the participants is far from unambiguous, however, as the stories of the few who mention positive thinking illustrate. 'I have to be an optimist. If I wasn't an optimist, I might have been dead already,' Ivan tells me. Contrary to how this may sound, however, Ivan does not see positive thinking as a guarantee for positive outcomes. This becomes apparent when he gives a couple of examples of instances in which his optimism was important. At one point, Ivan's haemoglobin level was low, but instead of surrendering to the weakness and fatigue this caused, he maintained a positive outlook and started taking walks. During our conversation he does not say anything about the result of these walks, whether or not they caused his haemoglobin level to return to normal. He does not seem to consider this important. Rather, the moral of the story is the fact that his optimistic attitude enabled him to take action in relation to his disease. His positive thinking made it possible for him to do something, and this was more important than the results of his actions. His second example follows the same pattern. Here, thinking positively gave him the strength to defy the doctors' prediction that his kidney failure would progress to a state in which his kidneys would no longer produce any urine at all. In his account of this event Ivan also does not disclose any results. What was important was not whether his defiance of the doctors' prediction was correct but the fact that he defied them at all. Here, optimism functions as a means whereby Ivan may act on himself and the objects and others around him, not primarily as a means whereby he may ensure positive outcomes. What his optimism does is provide him with a greater scope of action.

According to Filips, quite conversely, positive thinking has the power to generate positive outcomes. When I ask him what conditions he thinks have to be met in order for a transplanted kidney to match his body, he replies:

> I think that the first condition is willingness, that is, that the person in question wants to undergo transplantation. The second condition is that the person hopes to have a positive result; that he's in a good mood, thinking positively. I saw a person who was concentrated on the idea that he would die soon. Then it really went bad.

Here, the idea that the thoughts we think may have a direct influence on the outcomes of complex and uncertain events is strikingly present. Just as positive psychology would have it, Filips seems convinced that if he does not think positively, his body will reject the transplanted kidney. Lidija shares this conviction to some extent. At the time of our interview, she has quite recently experienced a failed transplant. Her body rejected it almost immediately after it was inserted. Lidija is ambivalent as to the nature of her thoughts and feelings before the operation. She was happy when she got the call from the hospital telling her that there was a kidney for her, but she could not help worrying. She was afraid that the transplant would not start functioning, as had happened with her first transplant. But she was not thinking negatively, she tells me: 'The tests for the second kidney were very good, [and] I hadn't been thinking that it wouldn't work or that kind of thing, but my temperature rose and the rejection process started.'

Thus, prior to receiving her second transplant, Lidija was simultaneously happy and worried, but managed to keep negative thoughts at bay. Among the participants, Lidija is not alone in experiencing such emotional and reflective ambivalence before undergoing transplantation. But if thinking positively and feeling optimistic are as important as the imperative of positivity would have it and as Filips and Lidija to varying degrees contend, how does being ambivalent affect the outcome of the procedure? Does one have to avoid contemplating the risks altogether in order for the transplantation to be successful? And if one could not help having ambivalent thoughts and feelings, how should one evaluate the impact of this ambivalence on the outcome of the procedure in retrospect? These difficult questions seem to be occupying Lidija's mind at the time of our conversation. To the extent that she makes herself responsible for her own thoughts and considers them to be of some importance for the outcome of the procedure, Lidija is aligned with the normative lines of the imperative of positivity. But at the same time, she questions the significance of her thoughts, given that, although she worried some, she did not think negatively and did feel happy. According to her own evaluation, it seems, if her thoughts and feelings had been crucial for the outcome of the procedure, it would have been successful. Thus, there is doubt in her mind about the power of positive thinking. But in both Lidija's and Filips's accounts, the force with which the imperative of positivity makes persons individually responsible for their thoughts is striking, and there exists no neutral authority that actively assists patients in avoiding negative thoughts and in evaluating the nature and impact of their thoughts in hindsight.

The moral and normative force of the imperative of positivity is even more striking when it is criticised. When I ask Stanislav if he would like to have any support other than medical, he replies, 'Oh, God forbid! It really annoys me when someone comes and starts teaching me how I'm supposed to live my life, someone with healthy kidneys, who feels well, tells me, "Why are you sitting here instead of running around feeling happy?" That really makes me angry.' Stanislav declines to receive any psychosocial assistance whatsoever rather than risk having a person instructing him to be happy. The fact that Stanislav views this risk as outweighing the other forms of assistance that a psychologist or occupational therapist, for example, can provide attests not only to the power inherent in the imperative of positivity but also to its ubiquitous presence. There is always a risk, Stanislav seems to say, that someone – someone in relation to whom one is furthermore in a position of inferiority – comes and tells you to think positively and feel happy, when what you actually need help with is managing your feelings of sadness and anger as well as your thoughts about past events and future uncertainties (cf. Ehrenreich 2009).

Veronica, unlike Stanislav, directs her criticism towards her fellow patients, or rather towards the journal published regularly by the national patients' association *Swedish Kidney Association*.

> Veronica – …They are very positive somehow, sometimes it gets a little unreal.
>
> Martin – They don't highlight the heavy issues, the difficult issues, or…?
>
> Veronica – Or, when they do interviews, sometimes they only interview those who are doing well and not the others. And I think that's why they don't have that many… subscribers…
>
> Martin - …because they paint a pretty one-sided picture?
>
> Veronica – When you're not feeling well you easily get irritated with that, because you… But it's good, too, that it exists, because then you can see that, well, it works, you can do more than you think.

The imperative of positivity is advanced not only by representatives of health care institutions, but also by the patients themselves. What irritates Veronica about the content of the patients' association's journal is that it is often optimistic to the extent that it fails to describe or to align with the way she lives and how she experiences her own life. In relation to her shifting condition, the constant positivity of the journal emerges as unrealistic. But its optimism is not unequivocally bad. Since it is anchored in the lives of persons who share her fate, it may sometimes function as an inspirational illustration of what is possible to do despite kidney failure and haemodialysis.

Clearly, then, the imperative of positivity exerts a powerful force.

Through its intimate intertwinement with the neoliberal ideals of responsibility, activity, and autonomy it accumulates into a line, in Ahmed's sense of the term, orienting individuals not only to monitor their thoughts in general, but also to sort some thoughts out and replace them with others. As my analysis has shown, however, it is difficult to accomplish an unequivocal alignment with this line since it is almost impossible to completely avoid worrying or thinking 'negatively' and to determine, in retrospect, whether one had been positive enough. Further, as Stanislav's and Veronica's accounts show, whether one is able to incorporate a positive message and begin living from rather than towards it depends on one's embodied situation at that very moment. If one does not feel well, if one's body dys-appears, for instance, a positive message may exacerbate one's condition rather than the other way around, since one is unable to align oneself with it. At such moments, it may spur feelings of anger and irritation, as Stanislav's and Veronica's accounts illustrate.

Summary of the chapter

In this chapter, I have analysed and explored three interrelated modes of coping that emerged in my empirical material. This analysis illustrated that it was primarily at the initiation of haemodialysis that the seriousness and chronicity of the disease really dawned on the participants. It was at this point that they became practically and existentially aware of the immense impact that the disease would have on their life. This spurred the need for finding ways to cope, which, as I have shown, was done in three interrelated ways. These three modes of coping were primarily oriented towards existentially and emotionally coming to terms with the disease and the dependence on renal replacement therapies. Or in other words, the modes of coping constituted three interrelated ways in which the participants attempted to avoid disorientation by trying to incorporate the disease and their dependence on the treatments into their corporeal schema so that they would be able to live from them rather than towards them, thereby regaining a sense of homelikeness in the world. Rather than being idiosyncratic strategies aimed at handling a life with chronic illness and invasive medical therapies, these modes of coping were intimately linked to pervasive normative orientations in the contemporary culture, such as positive thinking and a cultivation of acceptance in the face of overwhelming risks. Although they primarily constituted means whereby the participants emotionally and existentially endeavoured to come to terms with their situation, the three modes of coping were deeply intertwined with the practices in which the participants were engaged. This fundamental entwinement between the existential and the practical will become even more apparent in the next chapter where I move on to study the forms of patienthood that are enacted in the practice of haemodialysis.

5. The person in the patient – the practice of haemodialysis

In this chapter I turn to the haemodialysis practice. My interest is directed towards the forms of patienthood that are enacted in haemodialysis and how personhood, embodiment, and the medical body-as-object figure into this. In doing so I explore the transformation of persons with kidney failure into haemodialysis patients and study the interaction that takes place between patients and medical personnel. I also pay close attention to what is done during the treatment; for example, what nurses and patients do when they are together and what patients do when they are left alone with the haemodialysis machine. I begin by attempting to define what a patient is.

Patienthood

What is a patient?

Few scholars have endeavoured to provide this question with a comprehensive answer. One exception is anthropologist Katharine Young (1997), who, in her book *Presence in the Flesh: The Body in Medicine*, asks what makes a medical examination possible. Why are medical examinations not a violation of the integrity of the embodied person? The risk is imminent, she argues, since 'medicine inscribes the body into a discourse of objectivity' (Young 1997, 1).

Taking phenomenology as her point of departure Young contends that a person is an embodied self who, precisely through being a body, inhabits and experiences a world. Being inserted into the world in this way, a person is always already immersed in a situation and necessarily oriented. Thus, for Young as for phenomenologists in general, persons are always already embodied and social beings (1997, 1–32).

How is it, then, that medical examinations, which rely on an objectification of the body, do not necessarily violate the integrity of the embodied person? This is so, Young argues, because medicine is equipped with a number of spatial, temporal, and conceptual boundaries and frames that protect the 'body-as-self'[50] from the 'body-as-object'. What transpires in medical practice is a realm-shift through which 'the realm of medicine' takes precedence over 'the realm of the ordinary'. It is by means of this shift that persons are transformed into patients. A person becomes a patient when, in a medical context, his or her body-as-object is given primacy over his or her body-as-subject (Young 1997, 1–32).

Young is careful to point out that the transformation of persons into patients is never complete. Rather, the realm-shift is always 'an intermittent, periodic, or partial phase, layer, or aspect of the medical examination' which comprises 'a complex choreography involving the disposition, shift, removal, and replacement of boundaries' (Young 1997, 11–12; see also Thompson 2005). This complex choreography is required since it is impossible to completely dislodge the self from the body.[51] When the body is objectified, the person is still there, albeit on the periphery. As I pointed out in the introductory chapter, quoting Young, what is at stake is neither a contrast between 'mind and body, in which body is implicitly object, nor between subject and object, in which body is presumptively subject. The proper contrast is between body-as-self and body-as-object, and both of these are aspects of the experience of being a body' (1997, 5–6).

Thus, in medical practice a patient may very well experience the displacement of the self from the body. But the very possibility of such an experience tells us that the body has not been rendered an object completely. Rather, as I have already mentioned, the lived, human body is always

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[50] In order to achieve a more consistent terminology, I use the term 'body-as-subject' rather than 'body-as-self'.

[51] As Young herself and several other scholars have shown, even lifeless bodies and body parts are often experienced as retaining a degree of personhood (Young 1997; see also Sharp 1995, 2006; Høyer and Olejaz 2011; Shildrick 2012, 2013).

both subject and object. If this were not so, an objectification would be either impossible or unnecessary. If the body were only a subject, an objectification would be impossible. If the body were only an object, an objectification would not be necessary (cf. Høyer and Olejaz 2011). Thus there is always a subject present experiencing the objectification of his or her body; the body-as-subject experiences the body-as-object. Such objectifications come in many forms. In what follows, for instance, I will rely greatly on the distinction I made in chapter 3 between the ill body-as-object and the diseased or medical body-as-object. As we shall see, there is often an intense interplay between these two forms of bodily objectification.

Although Young's contribution to the definition of patienthood is important, it is not exhaustive. Her analysis lacks two important components. First, in not emphasising enough the embodied experience of illness that might have brought the patient to see the doctor in the first place, Young does not sufficiently take into account the patient's unique perspective on the illness, diagnosis, and actions undertaken during the medical examinations she studies (see Toombs 1992; Drakos 2012). As my analysis below will show, even though this perspective may become intertwined with others, and thereby altered, the sick person's embodiment of illness, disease, and patienthood always affords him or her a particular perspective.

The second component of patienthood that Young overlooks is its anchorage in laws, policies, and institutions. Although I share Young's view of patienthood as primarily enacted in medical practice, this very practice and the roles of the actors who participate in it are to a large extent formalised by various policies, regulations, and institutional frameworks. When a person seeks medical care, he or she formally becomes a patient, a role that provides him or her with certain rights and obligations in relation to society in general and medical institutions and their personnel in particular. Regardless of how and to what extent the person seeking medical care experiences the objectification of his or her body, at the medical institution and in relation to the care providers, he or she is a patient.

However, as I stated above, I accede to research that emphasises the primary significance of the practice of medicine and the interaction between the sick persons and the health care professionals in shaping the form and content of patienthood (Young 1997). But such an analysis should not exclude the formal and institutional framework that orients the practice (Magnússon 1996; Jönsson 1998). As Ahmed points out, institutions cannot be separated from the work that goes into maintaining them. While an 'institution comes to have a body as an effect of this work', 'becoming a "part" of an institution […] requires not only that we inhabit its buildings, but also that we follow its lines', she writes (Ahmed 2006, 133–134). Thus, institutions are not stable entities, but rather are deeply affected by the actions of those who are a part of them. However, one does not become a part of them unconditionally; one has to align oneself with their lines. Becoming a part of an institution or any other community requires that we turn in some directions rather than others, a turning that is anything but neutral. Just like diagnoses, or perhaps even more so, institutions 'hail' or 'interpellate' us, thereby forcing us to orient ourselves in particular directions (Ahmed 2006, 133–134). As we saw in the previous chapter, when they were diagnosed with kidney failure, some of the participants were immediately and acutely recruited into a medical institution, while others began to follow a future-oriented diagnostic line that promised a return in the form of a deferred initiation of treatment. In this chapter my focus will be directed towards the alignment of these persons, and to some extent also the medical personnel, with the lines of the haemodialysis institutions that I have studied. I am interested in what forms of patienthood and institutions the repetition of these lines creates.

A brief history of patienthood

Before proceeding with this analysis, the historicity of patienthood must be briefly addressed. Patienthood is a far from stable category and has undergone several quite radical transformations since the eighteenth century. According to Carl May and Nicola Mead (1999, 77), until the end of the eighteenth century and before the birth of modern biomedicine, 'medicine was by its very nature holistic and patient-centred'. The only way a doctor could understand and diagnose a patient's ailments was by listening carefully to his or her story about them or by observing the surface of his or her body. There existed no technologies capable of accessing the bodily depths of living persons, assessing what was going on under the surface (Reiser 2009, 1–2). At this time, moreover, illness was intimately linked to morality. It was the doctor's duty to determine whether the cause of illness was to be found in a moral deficiency or a bodily dysfunction. Letting the patient as a social being emerge in the clinical encounter was thus part of the medical examination itself (May and Mead 1999, 77). This began to change at the very end of the eighteenth century when clinical medicine was paired with pathological anatomy. The knowledge that had been gained about the ravages of disease inside the bodies of deceased persons began to orient doctors' actions in the clinic. Now the stories patients told about their ailments began to lose significance, in favour of the search for 'signs detected through the inspection of their bodies – through touching, looking and listening' (Svenaeus 1999, 46). With the invention during the nineteenth and early twentieth century of technological tools that improved the detection of signs of disease in living bodies, and as clinical medicine increasingly moved into the hospital, the significance of the patient-as-person continued to decrease. 'What mattered in this heroic age of scientific innovation and discovery was the uncovering of discrete and identifiable pathologies,' May and Mead write (1999, 77). Thus, it was in conjunction with the birth and application of modern medicine that the diseased body-as-object rather than the sick person-as-subject emerged as the main focus of medicine.

This development characterised the practice of medicine in both Sweden and Soviet Latvia. In Soviet Latvia health care became centralised into a system of regional polyclinics, where the care provided was profoundly paternalistic (McKewitt, Luse, and Wolfe 2002; Larsen and Kilkuts 2005; Luse and Kapina 2011). In Sweden the organisation of services was centralised in 'district health authorities' and much of the care was carried out in large hospitals. In the late 1970s, however, there was growing criticism in Sweden of the care performed in these hospitals. It was accused of being dehumanising, non-service minded, and incapable of meeting patients' needs (Axelsson 2000, 48–49). Seen from a global perspective, this criticism was clearly part of a transnational movement. According to May and Mead, this movement had its roots in the interwar period and the emergence at this time of the psychological notions of 'personality' and the 'unconscious' as modes of explanation for patients' non-compliance. Despite this rather paternalistic initial purpose, May and Mead argue, the entry of these ideas spurred a development in which the doctor–patient relationship – owing much to the work of Michael Balint in the 1940s and 1950s – began to be viewed as 'intrinsically therapeutic'. Here, the notion that the patient should be seen and treated as a 'whole person' gained in importance (May and Mead 1999, 80–82; see also Kaufman 2005, 66). From the 1960s onwards the struggle to increase the patient's influence over the care provided continued and was fought on many fronts. According to Reiser, the struggle 'was marked by a confluence of four movements, a civil rights movement, a women's rights and health movement, an anti-war and counterculture ethos, and a medical ethics renewal' (2009, 182). Interestingly, several social scientists and feminist scholars were also at the forefront (May and Mead 1999, 82), and from the 1970s onwards numerous scientific publications have criticised the neglect of the patient-as-person and the objectification of the human body taking place in modern biomedical practice (see e.g. Scheper-Hughes and Lock 1987; Kleinman 1988; Toombs 1992; Sharp 2000).

This struggle has not been without results. As the previous chapters have revealed, there is ample evidence, in previous research as well as in my own, of the emergence of a 'new' patient. I will take the opportunity here to briefly reiterate some of the central features of this 'new' patient. This is a patient who should be viewed and treated by his or her caregivers as an autonomous, empowered, and unique individual with particular needs and wishes (Hansson 2007; Karlsson 2008; Fioretos 2009; Idvall and Lundin 2009). Rather than being a passive recipient of medical knowledge, he or she should enter into a partnership with the caregivers and be considered an expert on his or her body and illness (Lundin 1997; Novas 2006). This 'new' patient is thus an active one (Barbot 2006; Rose 2007; Alftberg and Lundin 2012). He or she actively takes responsibility for his or her disease and treatments and gathers information about diagnoses and treatment alternatives. Moreover, he or she participates in the decision making and has the opportunity to choose among health care providers and treatments (Hansson 2006; Mol 2008). Thus, the ideal of the 'new' patient demands a transformation not only of the care that is given, but also of the way it is received. It should not simply be received. Rather, the patient is responsible for actively seeking and choosing the ideal care for his or her specific needs and wishes, and for actively participating in and becoming knowledgeable about the care he or she chooses.

Although to a large extent this is still not a fully realised ideal, its materialisation in policies and laws is becoming increasingly detectable. From the start of the 1990s onwards Sweden and Latvia both have passed laws and policies aimed at strengthening the role of the patient. Decentralisation and increased privatisation of services have also taken place, to a great degree transforming the patient into a consumer choosing between different treatment alternatives and providers (Tragakes et al. 2008; Anell, Glengård, and Merkur 2012). In Sweden, several studies attest to the materialisation of the ideal of the new patient in medical practice, of which the increasing transition towards and appraisal of self-care is but one indication (see Lundin 1997; Hansson 2007; Fioretos 2009; Alftberg and Hansson 2012). In Latvia, however, despite the processes on the level of law, policy, and organisation, a similar transformation of medical practice is not as clearly identifiable. In a study of contemporary mental health care in Latvia, for instance, Luse and Kapina found that the 'status difference' between doctors and patients had even increased since the country gained independence from the Soviet Union. While the status of doctors rose during the 1990s, 'the liberal economic reforms' implemented during this decade caused an increased marginalisation of persons afflicted with mental illness, Luse and Kapina argue (2011, 70). As the above indicates, the neoliberalisation of health care that has taken place in both Sweden and Latvia – in the form of, for example, decentralisation and privatisation – may have both similar and different outcomes in different national contexts, a fact that will become increasingly clear as this and the following chapters progress.

During my fieldwork at the haemodialysis unit in Riga, it was evident that the medical professionals working there had an ambition to include and inform the patients more. Dr Liepa, for instance, told me, 'We have to talk, talk, and talk with the patients; we have to learn how to listen to them.' But this was an ambition that Dr Liepa and her colleagues struggled to realise, a struggle that, in her mind, was due mainly to economic constraints. At the time of my fieldwork in Latvia in 2009 and 2010, the country was in its deepest financial crisis since independence. This impacted the provision of health care significantly. To receive a reasonable salary, Dr Liepa had to work at least two jobs at the hospital, which affected the attention she was able to give the patients. In concluding her argument she said, '[The patients] have medications; they have machines and technologies and so on, but they don't have information right now.'

In addition to this economic explanation, it is reasonable to believe that the relatively short time that has passed since the fall of the Soviet Union also contributes to this situation. There is an overwhelming consensus among scholars studying the Soviet medical system that health care during Communist rule was profoundly paternalistic (see e.g. McKewitt, Luse, and Wolfe 2002; Luse and Kapina 2011). 'At that time', Latvian physician Guntis Kilkuts writes, 'the ideology was that the health care system took over the patient's disease' (Larsen and Kilkuts 2005, 55). Once within the confines of a medical facility, patients were no longer responsible for their own health, and were neither permitted to participate in nor to influence the decision making. According to anthropologist Aivita Putnina, patients were viewed predominately as a passive collective whose well-being could be ensured only by means of an undisturbed implementation of biomedical knowledge. This view, Putnina argues, caused a vast rift between patients' and professionals' perceptions of the events that transpired within the confines of medical facilities (1999, 94). This 'estrangement between doctors and patients' was also to a great extent political in nature. While patients often saw their illnesses as caused by political oppression, medical professionals tended to dismiss many patients as malingerers (Skultans 1998, 21). As Luse and Kapina's study referenced above implies, there is much to indicate that this estrangement and lack of trust characterising the doctor–patient relationship still persists to some extent.

This does not mean that Swedish haemodialysis care, by contrast, is fundamentally holistic and patient-centred. During my first day of observations at Unit 1 in Stockholm, while I was drinking coffee in the staff canteen, a nurse explained to me that the care they provide at the unit is not holistic. For her, the holistic notion 'implies that you include the family and all other aspects of care', which they do not. 'We are specialised here,' she said, implying that their focus and responsibility is narrowly oriented towards the provision of treatment for a particular disease, that is, kidney failure.

The fact that the holistic ideal is set against the provision of specialised care in the quote above attests to the fact, pointed out by May and Mead, that the effort to make health care more patient-centred has had primary care and general practice as its primary focus (1999, 81; see also Charmaz 2000, 287). In fact, this is also the case with the majority of the social scientific and humanistic research on the doctor–patient relationship. For example, in considering 'the examination to be the quintessential gesture of medicine', as Young does (1997, 2), and describing 'the medical meeting' as generally 'a meeting between strangers', as Svenaeus does (1999, 243), a focus on primary care is not only maintained, but the doctor–patient relationship is also privileged at the expense of, for instance, the nurse–patient relationship. In this chapter, through a thorough analysis of the practice of haemodialysis, I will attempt to remedy this deficiency.

Patienthood in conventional haemodialysis

Haemodialysis is to a large extent a standardised biomedical therapy. At a majority of haemodialysis units worldwide, patients undergo the treatment three times a week, three to five hours at a time. That this is considered the minimum treatment dose for all patients is reflected in the *European Best Practice Guidelines on Haemodialysis*, according to which 'dialysis should be delivered at least 3 times per week and the total duration should be at least 12h per week, unless supported by significant renal function' (Tatterstal et al. 2007, ii5). Such standardisation, as Lock and Nguyen, among others, have pointed out, is a fundamental feature of modern biomedicine, which views the human body as a universal object that it is possible to treat and cure by means of the same methods everywhere (2010, 38; see also Thompson 2005, 253).

Three of the four haemodialysis units where I have conducted fieldwork follow the guidelines mentioned above. With just a few exceptions, patients go to the treatment unit three times a week and spend four hours connected to the haemodialysis machine. This is not the case at the self-care unit, however. Here patients have the opportunity to determine the frequency and duration of the treatment by themselves, which often results in treatment durations exceeding twelve hours per week. The character of the form of patienthood enacted at the self-care unit warrants its own discussion, and this will come later in this chapter. At this point, I wish to describe the standardised institutional lines, to use Ahmed's term, by means of which persons with kidney failure are transformed into haemodialysis patients at the other three units. According to the terminology of the medical literature on haemodialysis, the treatment carried out at these units can be labelled 'conventional haemodialysis' (see e.g. Pauly et al. 2009, 2915). This label denotes treatment regimes that follow the standardised scheme of four hours three times a week. Thus, what is intended is a particular form of temporal standardisation.

The temporality of the treatment is standardised in other ways as well. At all three conventional haemodialysis units included in this study, each day of the week is divided into dialysis sessions, typically with one session in the morning and one in the afternoon, and also, on some days of the week, with sessions in the evening and at night.[52] As a patient, one belongs to one of these sessions, which means that one always receives treatment either in the morning, afternoon, evening, or at night. Taken together, one's belongingness to such a session and the temporal scheme of conventional haemodialysis described above give rise to a strict and repetitive treatment schedule. Such a schedule might look like this: treatments on Monday, Wednesday, and Friday afternoon between 1.30 and 5.30 pm. Thus, haemodialysis is not only an immensely time-consuming treatment, but it also gives life a distinct and repetitive rhythm.

This standardised temporality is intimately linked to the standardisation of the body that takes place within the treatment practice and on which the treatment practice relies. It is the view and enactment of the body as a universal object – as being the same everywhere – that makes it possible to issue universal recommendations regarding the temporality of the treat-

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[52] During my fieldwork I conducted observations only during morning and afternoon sessions.

ment. Just as the body is objectified, so too is time. What matters is not the sick person's lived time, but the objective duration of the body's connection to the haemodialysis machine (cf. Toombs 1992, 3–4). As a consequence, the temporality of the movements of patients – as well as medical personnel – through the space of the units becomes highly standardised, and this, in turn, brings about a standardisation of the physicality of the space itself. The reverse is also true; the standardised spatiality of the units affects what movements can be made. As Ahmed points out, 'Space acquires "direction" through how bodies inhabit it, just as bodies acquire direction in this inhabitance' (2006, 12).

Since the spatiality of the three units has been arranged to accommodate the standardised bodies and temporality of the treatment, all of them are spatially strikingly similar. Taking centre stage are the haemodialysis machines and the hospital beds on which the patient lie during the treatment. At Unit 1 in Stockholm and the unit in Riga, the beds and machines are housed in large wards and lined up against the walls so that the machines are either behind or next to the head of the beds, which are placed against the wall. Thus, when they undergo the treatment, the patients lie with their heads close to the wall and their bodies extending out into the ward, with the machine either behind or beside their heads. At Unit 2 in Stockholm, the beds and machines are arranged in the same way, but the treatment takes place in smaller rooms. While at Unit 1 and the unit in Riga up to fifteen and twenty patients respectively may undergo treatment simultaneously, only four patients at a time share a ward at Unit 2.

Despite this variation in size, the wards are spatially very similar. All of them are strikingly medical and highly technological in nature. There is nothing in the physical environment that serves to mitigate the sense of being in a hospital. There are no decorations and no furniture of the kind you would find in a regular home. The only mundane thing is the TV sets that hang from the ceiling at the unit in Riga and from the wall next to each treatment place at the units in Stockholm. Each ward has a vantage point from which the nurses, and sometimes doctors, observe the patients while they undergo the treatment. This vantage point also functions in all three unites as a form of office space, where nurses may perform administrative tasks or open a particular patient's chart, and so forth.

Moving out of the wards, one will notice that the three units also have other spaces in common. Before and after the treatment, patients spend time in waiting rooms and dressing rooms and walk through corridors. There are also spaces reserved for the medical personnel, such as offices, canteens, storage rooms, and conference rooms. However, at the units in Stockholm patients are served a light meal during the treatment, while in Riga they eat in a small lunchroom before or after the treatment.

The transformation of persons with kidney failure into haemodialysis patients

It is along these institutional and standardised bodily and spatiotemporal lines that persons with kidney failure are transformed into patients in conventional haemodialysis.[53] At all three units, this transformation is initially performed without the presence of any medical personnel. The prospective patients arrive at the unit a while before the scheduled start of treatment and go directly to the dressing room. While some change into more comfortable clothes or even put on a patient gown, others only remove their outer garments and put on a pair of slippers or some other kind of indoor shoes. According to Young, 'taking off layers of clothing' is an essential part of the relinquishing of 'social personae' that takes place when 'persons become patients'. In a phenomenological vein, Young views clothes as objects that let us extend ourselves as embodied beings into the social world. Perhaps more than the surface of the body itself, clothes are what signals to others who we are, she argues, and by removing layers of them within a medical context we 'move toward rendering the body an object' (Young 1997, 14; see also Jönsson 1998, 93). Since haemodialysis patients most often just change into more comfortable clothes, this transformation is at most only partial for them.

If the clothing is essentially a voluntary matter, the weighing and waiting that remains is not. All patients are required to weigh themselves before the

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[53] In what follows I disregard the fact that sick persons formally become patients as soon as they enter the treatment institution. Instead I take inspiration from Young's (1997) and Jönsson's (1998) more dynamic analysis of the practical and interactional transformation of persons into patients.

treatment begins. In the context of haemodialysis, this normally rather mundane task carries deeply medical connotations. It is by measuring their weight that the persons with kidney failure, who are now on the verge of becoming patients, are able to report to the nurses responsible for managing their treatment how much fluid should be removed from their bodies during the treatment. All of them are invariably overhydrated when they arrive at the haemodialysis unit. Because their kidneys have lost the capacity to produce urine, all the fluid they have ingested since the last treatment session has stayed in their bodies, and this excess fluid is measured in kilograms. By calculating the difference between the weight before the treatment and the so-called 'dry weight' – which is what a patient weighs without being either under- or overhydrated – one arrives at the amount of fluid that needs to be removed from the body during the treatment. The dry weight, then, is the 'ideal weight' which every treatment session aims to reach (Lindberg 2005, my translation). To check whether this goal has been fulfilled, all patients weigh themselves again after the treatment.

The weighing is thus the first instance during the initial phase of the treatment at which prospective patients enact and encounter their body as a medical object. This particular version of the body-as-object is not neutral. Rather, it is fundamentally moral in that it displays in quantifiable and ostensibly unequivocal terms whether the sick person has ingested too much fluid during the time separating two treatment occasions. If he or she has drunk too much, the treatment will be more demanding, and if this continues over the long run, his or her condition will deteriorate radically. Since it translates directly into the configurations that the nurses make to the haemodialysis machine, the weight constitutes an essential value. This particular manifestation of the medical body-as-object comprises a significant sequence in the transformation of persons into patients in haemodialysis.

After weighing themselves, the prospective patients at the unit in Latvia might have lunch with their fellow patients in the lunchroom. Otherwise, if they eat after the treatment, they go directly to the waiting room, where some of their fellow patients have probably gathered. 'It is in the waiting room that persons await realm-shift, and await, too, the cues that tell them when to shift realms,' Young writes (1997, 17). I want to argue, however, that the waiting that takes place in the waiting room is itself part of the realm-shift. As ethnologist Anita Beckman points out, when one is forced to wait as a consequence of circumstances external to oneself, one's subjectivity becomes circumscribed (2009, 172–176). Rather than inhabiting the world as an outwardly oriented person, one becomes the object of other persons' actions, a state of being that, as we saw in chapter 1, constitutes one of the meanings of the word 'patient'. The waiting room is also essentially where the prospective patients, for the first time in the course of the day's treatment, become lumped together as a collective (cf. Jönsson 1998, 277). It is not just their inhabitance of the same spatiality that brings about the formation of this collective, but also their embodiment of the same disease. All patients reside within the confines of the waiting room for the same reason: they have been diagnosed with kidney failure and require haemodialysis treatment. This is something they are all aware of and, as I have shown elsewhere (Gunnarson 2015), something that greatly affects their interaction with one another.

What Young's contention above brings to light is the significance of the cue provided by the medical personnel, which ends the waiting, for it is by means of this cue that, to use Althusser's terminology, the prospective patients are hailed as patients and recruited into the institution. This may be seen as the decisive moment, in conventional haemodialysis, at which persons become patients. As Young points out, however, 'there is no single moment of transition between realms', and 'because enclaves of one realm […] extend into the other, the transformation is never complete' (1997, 15–16). These are qualifications that will prove to be of great importance in the sections to come.

Waiting is also the next step in the sequential transformation of persons into patients at the units in Stockholm, though in this context the waiting does not always take place in the waiting room. Sometimes the doors to the ward in which the treatment takes place are open and the designated bed to which a particular prospective patient has been assigned is available. If so, he or she may wait at that treatment place for the cue from the nurse, as it is the availability of the nurses that determines when the treatment can start. In this instance, unlike at the unit in Riga, the collectiveness enacted in the waiting room does not take place, and the person's transformation into a patient is essentially individual.

Perhaps, then, it is when the nurses arrive and the patients lie down on their beds that the final transformation takes place that turns persons into patients (cf. Jönsson 1998, 148). For it is then that the nurses begin to treat their bodies, actively and practically, as objects designated for medical scrutiny and intervention. However, as we shall see in the sections to come, it is often more complicated than this.

Once the treatment has finally been initiated – when the nurses have connected the patients to the machines, measured their blood pressure, and their blood starts to flow through the haemodialysis filter – a long period characterised by uneventfulness begins, and if no complications occur, it lasts until it is time to terminate the treatment, at which point the nurses return to the patients. The patients are thus dependent on the availability of the nurses also for the termination of the treatment and their return to personhood.

In summary, then, it is evident that the institutional lines created through the repetition of the standardised corporeality and spatiotemporality that characterise conventional haemodialysis to a large extent determine the nature of the transformation of persons into patients and patients into persons that takes place here. When one aligns oneself with these institutional lines, and consequently becomes a haemodialysis patient, one's movements become governed by the strict temporal rhythm of the treatment. Further, one comes to embody a restricted mobility, not least because one spends so much time confined to a bed, but also because one only has access to a limited number of spaces and is required to perform certain tasks before and after the treatment. Finally, one's alignment with these lines entails one's thematisation of and orientation towards one's own body as a medical object and one's dependence on the cues and availability of the medical personnel for the initiation and termination of the procedure.

Haemodialysis patients' views on patienthood

Before investigating in more detail what it means to align oneself with these institutional lines, I would like to explore briefly how the haemodialysis patients whom I have met describe and relate to the concept of patienthood more generally. When I asked them if they consider themselves to be patients when they undergo the treatment, a majority of those undergoing conventional haemodialysis said yes, while a majority of those conducting self-care said no. I will discuss in depth later in this chapter why persons conducting self-care haemodialysis might not as self-evidently identify themselves with the role of patient. At this point, I direct my focus towards the persons undergoing conventional haemodialysis.

Why do a majority of the persons undergoing conventional haemodialysis consider themselves to be patients during the treatment? Indra gives the following explanation:

> Home is home, but here everybody has his or her own problems, and when dialysis ends everybody hurries home, no one longs to stay here any longer. Before dialysis, yes, we eat together and talk, tell each other our problems. But home is home, it's different there.

Indra does not elaborate further on what the difference between her home and the unit really consists in, but she clearly prefers being at home to being a patient at the unit. Dmitry's words may be helpful in understanding this better. Dmitry considers himself to be a patient since the hierarchy at the unit is so apparent. He goes on to say, 'In my everyday life I can build this hierarchy myself, and I feel like the owner of my situation. Here, you are totally dependent on professors, doctors, nurses…' Tomas describes it similarly. When I ask him why he considers himself to be a patient, he says, 'Well, I have to do what they tell me to do, at least regarding some things.'

As numerous scholars have pointed out, the relationship between patients and medical practitioners is characterised by a fundamental asymmetry, an asymmetry that persists despite the patients' right to choose, participate in, and even discontinue treatment. According to Svenaeus, 'the medical meeting' is asymmetrical 'in the sense that the patient is the weak help-seeking party asking for aid from the expert in health matters – the doctor, nurse or some other medical personnel' (1999, 243). As such, this meeting is also an encounter between two asymmetrically valued forms of knowledge in which the scientific knowledge embodied by the medical practitioners takes precedence over the experiential knowledge embodied by the patient (Drakos 2012, 186).

In addressing the intimate relationship between her presence at the treatment institution and her embodiment of the role of patient, Indra highlights another form of asymmetry, another reason why patients have to do what medical practitioners tell them to do. This asymmetry has to do with the lines that the sick persons are required to follow in order to become patients. As we saw above, in the context of haemodialysis these lines are characterised by a strict temporal rhythm, restricted mobility, an orientation towards one's own body as a medical object, and dependence on the cues and availability of the medical personnel. What Indra and Dmitry implicitly suggest in their accounts is that, through aligning themselves with these lines, their dependence on the medical practitioners becomes institutionalised and spatiotemporally materialised, and thereby inseparable from the sheer spatiality of the treatment unit. What is thus created is a specific spatiality – the conventional haemodialysis unit – which is impossible to separate from the particular form of patienthood enacted there (cf. Jönsson 1998, 115). According to Indra, Dmitry, and Tomas, therefore, being a patient entails not only subjecting oneself to the actions and knowledge of someone else but also aligning oneself with the orientation of a specific spatiality: the treatment unit.

It is interesting to note, finally, that patienthood, in all three accounts above, is described in negative terms. Patienthood is something one wants to escape, something that is intimately linked with dependency and inferiority. The question then arises: how do haemodialysis patients in general and conventional haemodialysis patients in particular experience and manage the significant part of their lives during which they are patients? I will devote a large part of the remainder of this chapter to attempting to provide this question with an answer.

Repeating one's way to habit

As became evident in the previous chapter, persons who fall ill with kidney failure do not of their own free will become part of the health care institution that diagnoses and treats them. Rather, they are told that they have a particular disease and that this requires them to undergo particular therapies. Thus, they are actively recruited into the health care institution. They are hailed as kidney failure patients and required – if they wish to survive – to align themselves with particular institutional lines. In the previous chapter, the participants emphasised the need to accept and not overly thematise this requirement. If one thinks too much about and refuses to accept one's embodiment of the disease and dependence on haemodialysis, and perhaps later transplantation, they told me, one's situation will become even more difficult. Through accepting, monitoring one's thoughts, and thematising one's kidneys as lost, however, one may become able to start incorporating one's embodiment of the disease and dependence on renal replacement therapies into one's corporeal schema, at least existentially and emotionally. But as I hinted at then, this process of incorporation is characterised by an intimate linkage between the existential and the practical, a link that will become even more apparent in what follows when the participants describe the process by which they got used to haemodialysis.

When I meet Eva in November 2010 she has been undergoing haemodialysis for two and a half years. This is how she describes the thoughts she had before having the treatment for the first time: 'Well, I wondered how it worked [laughs]. But they [the nurses] were very good at explaining. But it looked a little scary, it did, but now I've got used to it.' When I ask her later in the interview how it is that one can get used to the treatment, she says:

> Well, it's not so much fun but I've got used to the fact that I need it to feel well. Because sometimes when you don't feel well and you go here [the haemodialysis unit], the day after, then you feel better. That is, you don't feel good the same day you have dialysis, but the day after you do, and if you're home one day more without dialysis, then you feel that you need it.

Many of the participants describe this process similarly. Ivan says that he has 'no other choice' but to get used to haemodialysis, while Indra tells me that it is her awareness that she needs it which has made her get used to it. Thus, the getting-used-to the treatment has two sources: one's acceptance of the objectively established medical fact that one dies if the lost function of the kidneys is not technologically replaced, and, as Eva's words indicate, the experience that the treatment, at least to some extent, improves one's health. Rather than viewing these as two separate sources, I want to suggest that it is the very alignment of the body as a medical object and the body as experienced which takes place here that makes this getting-used-to possible.

If one has not accepted and still overly thematises the need to undergo haemodialysis, the small improvement in health that the treatment generates might not be enough. But the reverse is also true: if it does not improve one's health at all, the medical fact that the lost function of the kidneys has to be technologically replaced might not suffice as a basis for getting used to the treatment. Here, the intertwinement of the existential and the practical might not be so obvious. But if we remind ourselves of the fact that from a phenomenological point of view, health is inseparable from a person's practical engagement with the world, this linkage becomes clearer. Then we realise how a person's getting used to the treatment hinges on the interrelated processes by means of which one existentially comes to terms with the absence of choice caused by the disease and in a practical sense comes to have a world through regaining a sense of health.

The intertwinement of the practical and the existential becomes even more obvious when a third source enabling haemodialysis patients to get used to the treatment is added. This source can be summed up in one word: repetition. This is how Tomas answers my inquiry about how spending so much time in a medical environment affects him as a person:

> No… affects, hopefully I get healthier when I have dialysis [laughs]. No but, affects, I mean, it's routines. You come here, you get connected, the coffee and sandwiches arrive, you watch TV and stuff like that, and they come and measure your blood pressure […], and then there's the additional check. Things move. It works, but it's the same thing all the time.

It is interesting that Tomas ends this quote by saying 'but it's the same thing all the time'. To make this statement consistent with what he has just said, he should replace the 'but' in this sentence with an 'and', since it is the fact that it is 'the same thing all the time' that allows the treatment to become routine, that allows things to move as parts of a predictable course of events. But the 'but' is understandable, since repeating the same thing over and over again can be experienced as dull and meaningless (see Ehn and Löfgren 2010). For the moment, however, I will focus on the positive outcomes of routines. Despite ending on a negative note, the message Tomas wants to convey, I believe, is generally optimistic. What he seems to say is that, since the medical environment has become routine, it does not affect him so much. He knows what is going to happen; he knows that things will move, and this knowledge makes it possible for him to existentially manage the many hours he spends at the haemodialysis unit.

Ahmed's (2006) conceptualisation of the notion of repetition is helpful in understanding what happens here. As discussed earlier, according to Ahmed, an institution consists of lines that direct its spatiality and the actions undertaken within it. This does not mean that an institution is 'simply given', for lines 'depend on the repetition of norms and conventions, of routes and paths taken' (Ahmed 2006, 16, 133). In fact, Ahmed points out, the very existence of lines is a result of repetition. Seemingly paradoxically, though, 'the repetition of the act of following makes the line disappear from view as the point from which "we" emerge' (Ahmed 2006, 15). This is not as paradoxical as it may sound. This is what happens, for example, when we acquire a new habit or incorporate a new skill into our embodied repertoire. It is by doing the same thing over and over again, by practicing, that something becomes habitual and we attain new skills. As Merleau-Ponty points out, what characterises such incorporated habits and skills is that we do not need to thematise them; we do not need to attend to how and why we do them, but we perform them as natural parts of our lives (2002, 164–165). This is the case also with the lines we follow, Ahmed argues. In being repeated, they become prereflective. As a consequence of the repetition itself, the repetitive acts become so familiar that they incorporate themselves into our body schemas and become part of the bodily here and now from which we live (Ahmed 2006, 19). This, she contends, is how we acquire an orientation, since orientations 'depend on taking [the] points of view', of which lines are an accumulation, 'as given' (Ahmed 2006, 14).

This tells us that simply being directed in line with a line does not make us oriented. When persons with kidney failure become recruited into the health care institution and begin to follow its lines, they are not from the outset fully oriented; as we saw in the previous chapter, encountering haemodialysis for the first time may be a shocking and disorienting experience. But by means of the repetitive acts and events of which the treatment consists, and, as Eva, Ivan, and Indra point out, through one's work of existentially coming to terms with one's dependence on it combined with one's experiences of its health-improving capacity, one may begin to experience the treatment as habitual and thereby take the points of view that it creates as given. As the following quote indicates, this habitualness may characterise not only the events that take place during the treatment but also the institutional spatiality itself as well as one's relation to the other persons who inhabit this space. During our second conversation I ask Dmitry why he feels he has adapted so well to haemodialysis:

> Precisely because you come here every other day. It's like visiting a bathhouse or a swimming pool or, as I said before, a fitness centre. Here's a group of people that I know. I know everyone, and not only here but at the transplantation unit as well, since I've been there several times. It's like coming home.

Due to the very repetition of the treatment – because he comes to the haemodialysis unit every other day – the institutional lines that Dmitry follows disappear from his attention, even to the extent that it becomes possible for him to compare the unit with other spatialities ordinarily experienced as familiar and habitual. To some extent, Dmitry's use of these comparisons most likely constitutes a way for him, in his conversation with me, to 'de-exceptionalize' and normalise his dependence on haemodialysis (see Amelang et al. 2011), but it would be a mistake to disregard the solid experiential base on which this strategy is founded. There is much to indicate that Dmitry actually experiences the haemodialysis unit as akin to a bathhouse, fitness centre, or even a home. What he does while he is there – routinely tending to the health of his body – is similar to what one does at a bathhouse or fitness centre. More striking is his reference to the unit as a home. From my point of view as an outsider, the physical environment of the haemodialysis units I visited was about as far from a homelike environment as you can get. However, it is not primarily the physical environment that Dmitry is talking about when he refers to the unit as a home; he is talking about the relationships he has developed with the people who inhabit it. It is apparent that it is the familiarity characterising these relationships that gives rise to his experience of the unit as a home. Dmitry's use of the word 'home' here echoes the terminology of both Ahmed and Svenaeus. For Ahmed, homelikeness constitutes an essential feature of a person's orientation in the world. It is when we are oriented that we feel at home in the world, she argues. Svenaeus, more specifically, links homelikeness to health. When we experience illness, he argues, we tend to lose our feeling of being at home in the world. Dmitry's use of the word 'home', then, can be seen as an indication of the fact that the repetition of the treatment has enabled him to incorporate the institutional lines along which haemodialysis is practiced, which in turn has allowed him not only to feel at home at the unit but also to orient himself away from, rather than towards, his ill body.

It is not the case, then, that haemodialysis patients remain unaffected by the events that take place during a treatment session and the spatiality in which these events occur. As the excerpts from my empirical material above reveal, by means of the continual repetition of the treatment, the patients incorporate new habits, a process that changes the way they bodily inhabit the world. What I have wanted to point out here is that this change is of a character that enables them to experience the treatment practice as routine, as a familiar course of events that takes place in a setting they have become used to.

That this process of routinisation also applies to the patients' relation to the treatment technology, the haemodialysis machine, was something that surprised me during my fieldwork. My preconception was that the machine as a material and technological entity would be a theme that our conversations would revolve around a good deal. But this was not the case. It was the interaction with the medical personnel and the other patients, the struggle to manage the feeling of being bound, and the slow passage of time during the treatment that became the primary topics of conversation relating to the haemodialysis practice. It was evident that most patients – and here we are concerned only with patients undergoing the conventional version of the treatment – stopped thematising the machine as a technological and material entity after a while. Dmitry, for example, tells me that he learned 'the approximate structure of the machine' early on but that he is now 'absolutely indifferent' towards its workings. Others immediately link my inquiries about the machine to the unpleasant situation that their dependence on it puts them in. Eva, for instance, directly associates the machine with an experience of being bound during the treatment. 'You feel trapped,' she tells me. 'You're stuck. You can't get up, which is pretty frustrating.' In other accounts the mundane presence of the machine in the patients' life becomes evident in the form of metaphors taken from their everyday life, in much the same vein as Dmitry did above. Indra and Tomas, for example, describe their relation to the machine in terms of friendship, giving it human characteristics. Offering a touching notion of friendship, Tomas tells me, 'It's simply a friend.' 'A friend?' I ask. 'Yes,' Tomas replies, 'since it keeps me alive.' In a similar vein, Indra describes the machine as a 'companion' helping her deal with her illness.

Of all the persons undergoing haemodialysis whom I interviewed, Sven offers the most elaborate account of how he sees the machine to be related to him as a person.

> When I look at this machine [turns to look at the haemodialysis machine beside him], it's like looking at the riding lawn mower that I've finally bought for the country house, which lets me mow the lawns quickly and efficiently. And then when I'm finished, I can just put it away in the shed or something. So by means of this [machine] I have achieved efficiency in a rational way, which enables us [refers to his family] to do other things that are more fun in our spare time, take a walk down to the lake or something like that. This way, we don't have to work like hell getting the grass cut […]. So I see the device here [turns again to look at the haemodialysis machine] as a kind of aid that I have in other contexts as well.

By using the riding lawn mower as a metaphor for the haemodialysis machine, Sven gives us a lot of information about his relation to the treatment technology. Like any other technological device that he uses in his everyday life, the haemodialysis machine is a tool that enables him to do other things, to engage in activities that he enjoys in the company of his family. What he also implicitly tells us, as Indra and Tomas do when they use the metaphor of friendship, is that the machine does not constitute a threat to his personhood. Rather, akin to friends and mundane technological tools, the treatment technology extends his reach into the world. In doing so, in becoming such a self-evident part of his life, it does not leave him unaffected. As the next chapter in particular will reveal, the entry and routinisation of the haemodialysis machine into the lives of persons with kidney failure transforms their corporeal schema in a way that reorients them (cf. Ihde 1993, 116; Mol 2008, 50). In this process, neither the person nor the technology is left unchanged (Koenig 1988, 469).

To sum up, then: by means of the repetition of the treatment, haemodialysis patients become able to incorporate the standardised institutional lines and the technological objects that they encounter in the treatment practice into their corporeal schemas. This tells us that the practical repetition of the treatment is not external to the existential work of coping with it. Just as their incorporation of the institutional lines orients their attention away from these lines, the patients' acceptance of their disease and their dependence on the treatment lays the foundation for such incorporation. But this work is never completed once and for all; both sides of the equation have to be cultivated. In what follows, I move closer to the practice of haemodialysis and explore the processes described above more closely.

The familiar nurse and the simultaneous presence of the body-as-subject and the medical body-as-object

In the practice of conventional haemodialysis, nurses are the most active occupational group. They connect patients to the dialysis machines, monitor the progress of the treatment, and manage its termination. As we shall see, this means that they interact with the patients much more than doctors do. This interaction is at its most intense at the beginning and end of the treatment, during the initiation and termination phases (cf. Koenig 1988). During the hours that elapse between these two events, however, the interaction between nurses and patients is typically restricted to a brief 'How are you feeling?' during one of the repeated measurements of blood pressure. I will return to this uneventful middle part of the treatment later in this chapter. My focus now will be directed towards the events that take place during the eventful start procedure of the treatment.

The following is an excerpt from the field notes I made during my observations at Unit 1 in Stockholm.

> It is early morning at Unit 1 and none of the patients who receive their treatment in the part of the ward where I am conducting my observations have arrived yet. Eva, who is usually the first to arrive, will be late since she goes swimming every Wednesday morning. Therefore Annika and Julia, the two nurses responsible for these patients today, have nothing to do, and take the opportunity to head off to the lunchroom for a cup of coffee. On their way out, they ask their colleagues to set off the alarm if any of their patients arrive. And, indeed, shortly after they leave the room, their first patient enters the ward. The patient in question is Maria, a woman in her fifties. Maria wears a patient gown over her clothes and she covers the distance from the entrance of the ward to her treatment place supported by a stick. When she arrives, she sits down on her bed and starts untying her shoes. After a while, one of the doctors approaches her, and they chat for a while. At this point, Annika re-enters the ward. She has a full teacup in her hand, and I join her as she walks over to Maria. When we arrive, Maria has changed her shoes for a pair of knitted socks and is sitting on the edge of the bed with her back to us reading a note from the doctor. ‘Good morning Maria,’ Annika says. ‘Good morning,’ Maria replies. Maria lies down on the bed. ‘Have you weighed yourself?’ Annika asks. ‘Yes,’ Maria replies. ‘That’s good.’ However, Maria first gives Annika the wrong number, but quickly corrects herself. Then Annika asks what she usually drops down to [her dry weight], and Maria replies ‘57’. ‘Shall we aim for that then?’ she asks, and Maria answers ‘Yes’. ‘Has your CDC [her vascular access] functioned well?’ Annika wonders, and Maria answers this question affirmatively as well. During the course of this conversation, Ali, a nurse working in one of the other sections into which the ward is divided, has arrived. Since Julia is still in the lunchroom, he has agreed to assist Annika in starting Maria’s treatment. During the start-up phase, their work is divided in such a way that Ali makes the necessary configurations of the machine while Annika connects Maria to it. Thus, Ali is mainly directed towards the machine, while Annika is directed towards Maria. I stand at the foot of the bed. Soon Maria and Annika’s conversation leaves

> the subject of Maria's CDC and passes on to the topic of this morning's chilliness. However, they speak so quietly that I have a hard time hearing what they say. But I hear that after a while they switch subjects again and start talking about different kinds of berries, blueberries and raspberries, for instance. In the middle of this conversation Ali breaks in saying '1.9', a number that Annika immediately writes down, before continuing her discussion with Maria. But then Annika suddenly returns to the state of Maria's CDC, asking again, this time in the form of a statement, 'Your CDC seems to be working well?' And Maria replies affirmatively. Then the conversation once again leaves the realm of medicine and starts revolving around Annika's and Maria's common connection to Norrland, a region in the north of Sweden. Here, Maria leads the conversation; she asks the questions and Annika provides the answers. The conversation is thus primarily about Annika's and not Maria's connection to Norrland.

This is in many ways a typical example of what transpires during the start-up procedure of a conventional haemodialysis session. I will therefore draw on it in the following discussion in order to make some statements about patienthood in conventional haemodialysis.

If the treatment as a whole proceeds without any unexpected complications, the start is the part during which the patient's body as a medical object is most actively enacted. This is where the connection of the patient to and the programming of the machine take place. This is also where the amount of fluid to remove and the function of the vascular access are discussed, and where the measurement of the patient's blood pressure and the evaluation of his or her illness experience according to a scale of ten grades are performed. These events take place within a setting that defines Maria as a patient and Annika as a nurse, and 'in contrast to everyday meetings', where the purpose of the meeting is often the meeting itself, 'the aim is specified beforehand' (Svenaeus 1999, 244).

What is striking in the episode above, however, is how little the actions that are undertaken figure into the communication between the nurses and the patient. Annika, Maria, and Ali do not thematise these actions. Instead, they discuss themes of a more personal character. Clearly, the need to articulate, to put into words, the different stages of the start-up procedure has disappeared. This is an effect of the duration and frequency with which the treatment is repeated, which I discussed above. Conventional haemodialysis is a standardised and therefore predictable procedure, one that soon becomes habitual for the actors involved (cf. Koenig 1988). Annika and Maria know what is going to happen and what they are supposed to do. To use Merleau-Ponty's (2002) terminology, they have incorporated the procedure into their habit bodies. And this creates room for them to meet as persons (cf. Magnússon 1996, 94).

What is further evident is that Maria and Annika already know, before this particular encounter takes place, that they have a common connection to Norrland. During the start-up procedure, their conversation almost seamlessly glides over to the theme of Norrland – no inquiries about the other's place of birth, for instance, precede this shift. Undoubtedly, this is not the first time Annika is starting Maria's treatment. They have met under these circumstances on numerous occasions. Annika and Maria are not familiar just with the actions of a medical nature that they undertake. They are also familiar with each other. This familiarity is clearly both a product of the habituation of the medical tasks that are performed and a means whereby Annika and Maria orient themselves away from these tasks. It is also apparent that the conversation they have is not primarily the result of some professional method used by Annika, the nurse. During the episode it is not primarily Annika who asks the questions, thus getting to know the patient as person, but to a greater extent the other way around. Consequently, rather than being a feature deliberately added to the treatment, the personal character of the exchange is essentially due to the temporal nature of the interaction – its duration and repetitiveness – combined undoubtedly with the sincere interest of patients in the nurses' personal lives, and the other way around. When there is no longer any need to discuss the different stages of the starting procedure, and when the nurse and patient in question have met a number of times, a temporal space opens up which is almost automatically filled with personal stories, and each encounter offers a possibility for them to pick up where they left off last time, thus deepening their relation.

This does not mean that the patient's medical body-as-object is not there. It is there already from the outset. When she arrives at Maria's treatment site, Annika immediately takes command of the situation. She is initially the one who asks the questions, while Maria responds. But Maria is not for this reason merely a passive recipient of her own body as a medical object. Up until now she has enacted it herself; she has weighed herself and changed her clothes. And when, after their 'good mornings' have been said, Maria lies down, making her body accessible for the actions of Annika, she effects one of the most important transformations towards becoming a patient (cf. Jönsson 1998). At this stage, Annika is the more active of the two. By posing questions about her pre-dialysis weight, her dry-weight, the amount of fluid she wants to remove, and the function of her CDC, Annika evokes Maria's medical body-as-object as a simultaneously quantifiable and functional body. The information that these questions produce allows Annika and Ali to begin working hands-on with the start-up procedure. Thus, even though Maria and Annika soon begin discussing the weather, the medical body-as-object is still being enacted. During the course of their conversation Annika's hands are steadily at work connecting Maria's CDC to the machine, and although she is oriented towards Maria, her eyes can only momentarily meet Maria's before they have to return to monitoring the work that the hands are doing. Consequently, the actions carried out speak another language than the words uttered (cf. Mattingly 1998).

Thus, during the start-up procedure the medical body-as-object is constantly enacted; the patient is always there. And it is this constant presence of the patient that gives rise to and makes possible the abrupt interruptions that occur in Maria and Annika's personal dialogue. On two occasions, the medical body-as-object is abruptly thrown into the otherwise non-medical exchange. The first time this happens is when Ali – who aside from this utterance remains silent – says '1.9'. This number, which I do not know the meaning of, is thrown into the conversation at a point when Maria and Annika are discussing berries. This causes the exchange to come to a temporary halt, not least because Annika has to enter the number into Maria's medical records. Before long, however, they resume their conversation. But soon there is another interruption, this time enacted by Annika herself who, once again, inquires about the state of Maria's CDC. Unlike the first time, however, Annika phrases her question in the form of a statement. She says: 'Your CDC seems to work well?' and signals with her intonation that this is meant as a question, thus prompting Maria to respond, once again, affirmatively. But the fact that Annika chooses to phrase her question as a statement is important here, since it points towards the source from which she got the motivation to pose it in the first place. When she utters the statement, her unarticulated work of connecting Maria to the machine has reached a point where she may assess the state of Maria's CDC herself, and this is information that she thinks, or perhaps knows, that Maria is interested in. The source of Annika's 'question' is thus to be found in the work that her hands have been doing since the beginning of the start-up procedure. Consequently, the interruptions in Annika and Maria's conversation, if they are at all to be seen as interruptions, have their origin in the constant enacted absent presence of Maria's medical body-as-object during the start-up procedure.

To sum up, the episode above highlights two important and deeply interrelated aspects of the practice of conventional haemodialysis: the relationships of a personal nature developed between nurses and patients, and the habitual and background presence of the medical body-as-object. Interestingly, it is not just the patient – as the ideal of the new patient would have it – who emerges as a person, but also the caregiver. Through meeting each other repeatedly, patient and nurse become able to transcend the institutional lines that give them these roles. The standardised repetition itself accomplishes its own disappearance. As Ahmed puts it, 'The repetition of the work is what makes the work disappear' (2006, 56). As a result, patients-as-persons and nurses-as-persons may extend into the space of the haemodialysis unit. This extension takes place since patienthood and nursehood – and the actions and objects associated with it – has been habitually incorporated into the corporeal schemas from which patients and nurses act. It may thus be absent from their attention, although they constantly enact it (see Leder 1990a; Merleau-Ponty 2002). Since extension, in this way, 'involves the acquisition of new capacities and directions', it expands 'what I can "have" and "do"' (Ahmed 2006, 115). Being able to add patienthood to one's prereflective perceptual and motor repertoire is therefore of great importance, since it is what allows one to transcend one's medical body-as-object and the actions directed towards it.

Here, once again,[54] we see how bodily objectification does not always

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[54] See the section entitled 'The body without kidneys' in the previous chapter.

limit or completely obstruct a person's extension into the world. Nor is it the case that the simultaneous enactment of the body-as-subject and the medical body-as-object necessarily constitutes a hazard that patients have to be protected from, as Young contends (1997). Rather, the body may, under some circumstances, be simultaneously subjectified and objectified without causing any detrimental effects. Unlike the process discussed in the previous chapter, in which the participants embraced and even created 'the body without kidneys' themselves, here patients and nurses relegate the medical body-as-object to the background of attention by means of a process of habituation. The medical body-as-object is thus enacted and acted upon in different ways in these two situations. In the first case, 'the body without kidneys' extended the reach of persons with kidney failure in the sense that it functioned as an object, as an 'orientation device', to use Ahmed's terminology (2006, 85), allowing them to initiate a process of reorientation. In the second case, patients and nurses were able to transcend the body-as-object enacted in the treatment practice by means of sheer repetition, by means of a process of habituation through which it was made both innocuous and absent.

The very existence of such variations attests to the danger in decontextualising bodily objectification and turning its detrimental nature into a general principle, as some scholars have tended to do (see e.g. Toombs 1992; Young 2005). What matters, as I have argued earlier, is not whether or not a bodily objectification takes place; what matters is the form it takes and under what situational and contextual circumstances it is enacted (cf. Weiss 1999; Thompson 2005). Under some circumstances the bodily objectification enacted may, contrary to what was the case above, severely obstruct the extension of particular embodied persons into the world. It may also be the case that the prevailing circumstances are capable of guaranteeing the unproblematic coexistence of only some, and not other, versions of the bodily subject/object configuration enacted. That this might be so will become evident in what follows.

When bodies do not align

In the case of conventional haemodialysis, the absence and innocuousness of the medical body-as-object hinges on the possibility of retaining the habitual character of the actions through which it is enacted. This is not always possible. Sometimes the habitualness is disrupted and the incorporated objects emerge as objects to which, rather than from which, attention is directed; they become 'excorporated', to use the terminology of Malmqvist and Zeiler (2010). In what follows I explore two such occasions, both of which took place at Unit 2 in Stockholm. The first episode occurred around ten o'clock on a Monday morning.

> I enter room 5 where four patients are currently undergoing the treatment. I soon realise that Rune, who lies in the far right corner of the room, is not doing well. He has an oxygen mask over his mouth and nose, and Joel, the nurse responsible for him, has tilted his bed so that his feet are above his head. Apparently, Rune's blood pressure has dropped drastically since the start of the treatment. Joel has therefore turned off the removal of fluid from his blood. But Rune continues to feel bad. Joel tries to begin a conversation with me about my study, but we are constantly interrupted by the alarm signals coming from Rune's machine. Joel repeatedly asks Rune if he is in pain. But Rune says no. He is not in pain, he says, but he does not feel good at all. Joel continually measures Rune's blood pressure and it is rising very slowly. After each measurement Joel informs Rune about the result, but Rune says that he does not think that the blood pressure is the cause of his suffering. 'It's not the blood pressure,' he says repeatedly, a statement that Joel does not respond to during the treatment. When it is finished, however, Joel instructs Rune to sit for a while on the side of the bed. Rune follows this command, and, when he is seated, Joel explains to him that his suffering did have to do with his drastic blood pressure drop. He tells Rune that his blood pressure only rose slowly because it took time for the fluid that was in his cells to enter the bloodstream. But Rune is puzzled about this explanation and eager to point out that the bad feeling permeated his entire body, not just his legs, where cramps are normally located. In response to this scepticism, Joel uses his expert knowledge about Rune. He asks Rune if he does not usually have chest pains when having experiences such as the one he just had. That is usually the case,

> Rune admits, but it was not so this time, he says. But Joel has more knowledge about Rune. His impression, he says, is that Rune's drastic reactions to the treatment come in waves. Therefore, he says, he believes that Rune is currently on his way into a difficult period and therefore recommends that he remove less fluid during the next treatment session. Today, Rune finished approximately one litre over his dry weight. But Rune points out that as recently as the previous treatment he dropped down to 58.2 kilos, just 200 grams over his dry weight. However, when Rune gets up to leave Joel says, 'I can tell that you have gained weight.'

The second episode took place two days later, this time around eight in the morning, during the initiation of the treatment.

> It is early Wednesday morning and Björn, a man in his eighties, arrives at his bed. Straightaway he lets the nurses know that he feels good. He tells them that it felt like he ran to the unit this morning. The first thing he says to me, as I approach him, is 'Today's a good day!' Björn is undoubtedly in a very good mood. He tells the nurses and me that he weighs less than usual today, which means that he will not have to remove as much fluid as he normally does. 'You should be happy about that,' he says. What adds to his good mood is the ease with which he performed this morning's physical exercises. These have been assigned to him by his physical therapist, and he is supposed to do them every morning for a year before meeting with the physical therapist again to 'show myself off', as he puts it. Later, when Björn's treatment has been started, he turns to me and proposes that we make a bet on his blood pressure. I respond that I am reluctant to do so since he probably knows this much better than I do. When Petra, the nurse who has connected Björn to the machine, starts the measurement, she reminds him to make his bet, and he guesses on a systolic pressure of 75. But it turns out to be much lower, only 66. 'It's strange that I can't feel it,' Björn says, and Petra clearly displays her concern. It turns out that Björn's blood pressure has been low for quite some time now.

In these two episodes the habitual incorporation of the medical body-as-object and the actions with which it is enacted are disrupted. As a result, it emerges as something towards which attention is directed. Or rather, what emerges is not the medical body-as-object alone but its relationship with the body-as-subject. As these two episodes show, the habitual incorporation of the medical body-as-object and the extension of patients and nurses as persons towards each other rely not only on the repetition of the treatment, but also on the alignment of the body-as-subject with the medical body-as-object. If the patient's experience of his or her body differs too much from the body as it is enacted by medicine, the habitual incorporation cannot commence. This also affects the relationship between patient and nurse. Rather than their interacting as persons familiar with each other, and discussing non-medical things, the medical body-as-object and its relation to the body-as-subject become their central objects of discussion in the episodes above. Consequently, the interaction that takes place is primarily one between a patient and a nurse rather than one between two persons, and the asymmetry characterising the medical meeting therefore emerges. Both episodes above end with the sick person's lived experience losing its legitimacy. This is particularly evident in the second episode, where Björn's health as measured by the blood pressure trumps his bodily feeling. When the nurse presents the result of the blood pressure measurement, the happiness with which Björn entered the unit is no longer warranted. Instead, he is told that he should feel concerned, which he clearly does.

One should be careful, however, not to view the relationship at stake in the episodes above as one between a purely subjective and a purely objective body. As I have emphasised on several occasions, a person's body is never purely subject or purely object. As patients with extensive experience of undergoing haemodialysis, Rune and Björn have incorporated aspects of the medical body-as-object into their self-understanding, into the embodied means whereby they experience their own health. This is a process which leaves neither the body-as-subject nor the medical body-as-object unaffected. What Rune and Björn have created and incessantly continue to enact is a synthesis of these two bodies (cf. Svenaeus 2009), what I call a 'sick body'.[55] This is a body that is never once and for all completed; it has to be continually cultivated. As persons with kidney failure undergoing haemodialysis, Rune and Björn therefore simultaneously live from and towards this sick body.

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[55] I will discuss the concept of the 'sick body' more thoroughly later in this chapter.

It is, for example, the creation and continual enactment of his body as sick that allows Rune to doubt Joel's explanation of his suffering. If Rune had not previously created an embodied synthesis between his experienced bodily sensations and the medical concept of blood pressure, he would not have experienced and interpreted the distress he felt in the episode above as something other than a blood pressure drop, and would therefore not have been able to contest Joel's claim. Since his blood pressure had dropped drastically many times before, he knew that he usually experienced this medical condition as cramps in his legs, not as something affecting his whole body, as he did this time. Similarly, the happiness Björn felt before receiving the result of the blood pressure measurement was due not only to the way he experienced his body, but also to his low weight. Since he had created a synthesis between particular bodily sensations and a low weight, the low number displayed by the scale only served to confirm the reasonableness of his relative feeling of health and happiness.

However, while Björn's happiness about his relative feeling of health is quickly undermined by the result of the blood pressure measurement, Rune fights a more even struggle. It is only when Joel meets Rune's synthesis of subject and object with a synthesis of subject and object of his own that his argument prevails. In order to convince Rune of the truthfulness of his model of explanation, Joel does not mobilise a pure medical body-as-object. Instead, he advances a body shaped by the knowledge he has about how Rune, as a unique embodied person, usually reacts to drastic blood pressure drops. It is by means of such a synthesis that Joel gets the final word in the conversation, telling Rune that he can tell, just by looking at him, that he has gained weight.

Now, what is at stake in this event is not only the alignment of the body-as-subject and the body-as-object, but also the alignment of two differently objectified bodies. When Rune experiences the difficult period during the treatment, his body dys-appears as something that hurts and is beyond his control, as an ill body-as-object. To him, this ill body-as-object does not easily map onto the medical body-as-object. In his view, his body-as-object as he experiences it during this difficult period cannot be understood through the medical concept of blood pressure. This is because it does not match the alignment of his ill body-as-object and his medical body-as-object that he has previously achieved. This tells us that the synthesis which brings about the sick body of the patients consists not only of their body-as-subject and their medical body-as-object, but also of their ill body-as-object. In order to create and habitually incorporate a sick body, haemodialysis patients have to align all of these aspects of their embodiment with each other. As Toombs's and Svenaeus's models for the process of falling ill indicated, the ill-body-as-object tends to be less alienated from the body-as-subject than the diseased or medical body-as-object (see Toombs 1992; Svenaeus 2009). While the dys-appearance of the ill body-as-object exerts an 'existential demand' signalling that it is my body that hurts (Leder 1990a, 92), the connection of the medical body-as-object to the body-as-subject has to be accepted by the sick person and enacted in the treatment practice, as we have seen. This might explain why Rune is at first unwilling to accept Joel's explanation of his suffering. However, due to the asymmetry that characterises the relationship between the ill body-as-object and the medical body-as-object in the context of medicine, as well as to Joel's own synthesis of them both, Joel's explanation prevails.

The always busy but mostly accessible nephrologist

As the above sections have shown, during a haemodialysis session patients interact primarily with nurses. But doctors – or nephrologists, as physicians specialised in renal medicine are called – are also present. At Units 1 and 2 in Stockholm as well as at the unit in Riga, all patients are assigned a nephrologist with whom they meet regularly. Usually these meetings take place during the treatment, at the patient's bedside. But physicians also go on rounds through the haemodialysis wards during which they check on the status of all patients. At the unit in Riga, these rounds coincide with the blood pressure measurements that the nephrologists carry out on two occasions during each treatment session. At the units in Stockholm, the nurses perform all blood pressure measurements and the doctors never go on more than one round per haemodialysis session. In addition to the scheduled meetings patients have with the nephrologist responsible for them and the brief interactions they have with physicians during their rounds, patients may also consult doctors by going through the nurses. If a patient, for instance, wants a prescription renewed, a test result explained, or an ailment discussed, he or she may ask a nurse to ask the doctor on duty to come by his or her treatment place. Beyond giving patients access to the doctors, this allows the nurses to function as gatekeepers. By assessing which questions and complaints require a nephrologist's attention, the nurses may help to alleviate the physicians' workload.

Undergoing haemodialysis, then, entails regularly meeting doctors. Although patients spend less time with doctors than with nurses, due to the repetitiveness of the treatment, the nephrologists soon become familiar faces for them. Patients' interaction with doctors, however, is often both more limited in time and more problem-oriented than their interaction with nurses. Ordinarily there is a problem that needs to be solved, a question that needs to be answered, or a body part that requires examination, and when this is done, the meeting is over and the doctor moves on to another patient (cf. Svenaeus 1999, 244). This echoes Mattingly's assertion that the 'hospital world operates in two time spaces. One is the time pragmatically expressed by the doctor – fast and efficient. […] The other is the time of the lesser health professionals: therapists, aides, sometimes nurses. Things move more slowly here' (1998, 21).

One morning at Unit 1 in Stockholm I observed the following meeting between a patient and a doctor.

> It is early Friday morning and I accompany nurses Inger and Lina as they approach Eva, who has just arrived at her treatment place. When we arrive, Eva tells us that her vascular access, which in her case is an artificial graft, had been examined the day before; they entered her graft with a camera to look for contractions. When Eva removes the bandage that has covered her graft since the examination yesterday, it turns out to still be swollen and bloody. Inger and Lina react quite strongly to this. They are not at all sure that they will be able to insert the dialysis needles into the swelling and they resolve to consult a doctor about it. However, the doctor will not arrive until 8, so the start of Eva's treatment has to be postponed. When the doctor finally arrives, he is able to establish quickly that there is no danger in inserting the needles into Eva's graft. But they will have to use a saline solution as blood-thinning agent instead of heparin and terminate the treatment after only 3.5 hours, since otherwise there is a risk of coagu-

> lation. Now that the doctor has given his verdict, he prepares to leave. But Eva takes the opportunity to call his attention to some other problems. She tells him that she has coughed blood and suffered from shortness of breath lately. The doctor replies that he does not have time right now: 'I have a lot of pressing matters to take care of,' he tells Eva. But Eva stands her ground and says that she wants to get this over with now. And without saying either yes or no, the doctor brings out his stethoscope and asks Eva to lean forward. He listens to her lungs and taps on her back and lets Eva know that it does not seem like she has a ruptured pleura but that he recommends a chest X-ray. He also listens to and confirms the plausibility of Eva's theory, namely that one of her bronchi has had a haemorrhage. But in order to examine this, he says, he has to go down her trachea, an examination that Eva reacts to with disgust. Fortunately, it is not necessary to perform such an examination right now, the doctor says, but what she should do is have a chest X-ray after the treatment. This seems to satisfy Eva, and the doctor gets up to leave. But before he leaves, he asks Eva if she has been given a time for discussing transplantation. 'Yes I have,' Eva says, 'the 14th of October.' This ends their interaction.

During my fieldwork I did not observe many doctor–patient encounters. Since I mainly accompanied nurses, I missed many of them, and when I saw that a doctor had already approached a patient, it felt ethically problematic to barge in. But the few I did observe shared many of the characteristics of the one I just recounted. What happens in the episode above is something out of the ordinary: Eva's graft is swollen and the nurses are unsure as to whether it is safe to insert the needles. So they decide to consult a doctor. The doctor is hence summoned to examine and assess the nature of a bodily alteration that stands in the way of the mundane actions which ordinarily initiate a haemodialysis session. Thus, when the doctor arrives, he does not instigate a personal conversation with Eva while his hands are occupied with assessing the severity of her swelling. Rather, since the swelling is out of the ordinary and the doctor has been summoned there to evaluate its severity, this is where both Eva's and his attention is directed. And when the task is completed, the doctor gets up to leave. There is therefore no room for any communication of a personal nature. Not even when Eva convinces the doctor to stay does the character of their interaction change. Eva hails the doctor as a doctor, as someone who might know why she has coughed blood and experienced shortness of breath, and in doing so she is primarily a patient. The doctor is in a hurry, and is reluctant to satisfy Eva's wish. But he does, and when he has finished listening to Eva's lungs and has decided to refer her for a chest X-ray, their meeting is over.

With the episode above in mind, it might perhaps seem strange that, during my subsequent interview with Eva, she describes the very doctor who assessed her swelling and referred her for the chest X-ray, who is also the doctor particularly responsible for her, as someone who is 'open', 'easy to talk with', and who on his own accord takes the initiative to come over and talk. According to Eva, he is a doctor you can 'talk about everything with and ask about everything'. However, perhaps this positive judgement is not so strange when one takes into account that what I witnessed above was an unscheduled meeting where a problem quite urgently had to be solved. What is more, Eva did not seem to expect anything other than strictly medical attention from the doctor. When he had attended to her lungs and initiated a process of further investigation, she was satisfied.

What Eva requested was an opinion on her ill body-as-object from a medical point of view. Essentially, she wanted the doctor to apply his specialised medical knowledge so that the dys-appearance of her body would end or at least be alleviated. The medical body-as-object therefore did not pose a threat to her. She saw it as an opportunity, as something that could bring her more in line with her intentions, which had been disrupted by the dys-appearance of her body in the form of shortness of breath and blood-filled coughs (cf. Thompson 2005; Zeiler 2010; Lundin 2012b).

The practice of self-care and home haemodialysis

I would like to turn now to the practice of self-care haemodialysis. To put it simply, in self-care haemodialysis, patients manage the treatment by themselves. They prepare the machine, program and connect themselves to it, monitor its progress, and terminate treatment. Moreover, since they have their own prescription, they may determine the frequency and duration of their treatment sessions. They conduct self-care either at home or at a designated self-care unit.

Self-care in this form does not exist in Latvia. If patients wish to manage their own treatment here, their only option is peritoneal dialysis, which is in itself a form of self-care.[56] In Latvia, however, it is primarily patients who live far away from a haemodialysis unit who are offered the opportunity to conduct peritoneal dialysis. The very existence of this form of treatment, though, attests to the fact that self-care, in both Latvia and Sweden, is and has long been an important aspect of the practice of dialysis in general.

Why does self-care haemodialysis not exist in Latvia? When I asked Dr Liepa this question she gave me two explanations: 'We don't have the tradition, and probably we don't have the money right now for this,' she said. When she elaborated on this statement she did not explain exactly what tradition she was referring to and admitted that no one had made any calculations of the costs involved in introducing self-care haemodialysis. But I believe it is safe to assume that the tradition she referred to as absent was the minimal experience of Latvian health care professionals in stimulating patient participation. As I have argued earlier, there is much to indicate that the form of medicine practiced during the Soviet period still affects to some extent how medicine is practiced in Latvia today. Further, at the time of my fieldwork, Latvia was in the midst of its deepest financial crisis since independence, and as Dr Liepa indicated, these economic hardships quite likely prevented an introduction of self-care haemodialysis at the time of my fieldwork.

During my study in Stockholm, on the other hand, I learned that big leaps were about to be taken towards radically increasing the number of patients managing their own treatment. One of the two sections of Unit 2, for instance, was to be turned into a self-care unit. Another unit, two floors above the existing self-care unit, was destined for the same transformation. This development was evident as well in my interview with Kers-

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[56] Three to five times a day peritoneal dialysis patients infuse a dialysis solution into their abdomen, letting it remain for a while before draining it along with the excess fluid and toxic waste products it has attracted, and this entire procedure is carried out without having to visit a hospital unit.

tin, the kidney failure coordinator, whose ambition was to make self-care, including peritoneal dialysis, the primary choice of all patients. What lies behind this development is a complex issue, which I will try to disentangle below.

At the time of my fieldwork – in the fall of 2010 and spring of 2011 – the proportion of patients managing their own haemodialysis was just below 10 per cent. Only two years later, in 2013, it had increased to 13 per cent.[57] This apparent development towards an increasing number of self-care patients was what prompted me to include this form of treatment in the study. I wanted to know why self-care was so acclaimed among care providers and policymakers, and whether or not the patients shared this conviction. More fundamentally, I wanted to explore what forms of patienthood were enacted in this form of treatment.

Among the persons undergoing haemodialysis whom I have interviewed, seven conduct or have conducted some form of self-care haemodialysis. All of them live in Stockholm. Carlos and Hans manage their own treatment at the self-care unit. Bengt and Sven used to manage their own treatment but were transferred to Unit 1 due to deteriorating health. At the time of the interview, Bengt conducts a form of semi-self-care where he inserts the needles himself and programs the machine but leaves the 'dressing' and 'priming' of the machine to the nurses. Sven, on the other hand, has given up self-care altogether since his left-arm fistula no longer functions. When one is right-handed, conducting self-care with a right-arm fistula is next to impossible. Veronica, like Bengt, conducts a form of semi-self-care at Unit 1, but unlike Bengt, she does everything but insert the needles. She had once intended to learn how to manage the whole treatment procedure by herself but never dared to insert the needles. Finally, there are Marianne and Camilla, who conduct self-care haemodialysis at home.

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[57] See http://www.medscinet.net/snr/rapporterdocs/SNR%20%C3%85rsrapport%202014_Webb.pdf, accessed 2015-08-13.

Enacting a personalised sick body

What struck me when I began analysing my interviews with the persons conducting self-care was that they constantly returned to the fact that this form of haemodialysis allowed them both to get to know their body and to adapt the treatment to themselves. Since almost all of them began their haemodialysis careers at a conventional unit, this was where their getting-to-know-their-body started. In many cases, it was what they learned here that promoted them to move on to self-care. When Carlos returned to conventional haemodialysis after living thirteen years with a transplant, he learned that undergoing only three treatment sessions per week was not enough for him. He realised that he was unable to align himself with the standardised lines of conventional haemodialysis. 'I can't adapt to dialysis. It can't be done,' Carlos tells me, and continues, 'I know where my limits are. I know that it's hard to "take off" a lot of fluid from me. I know that I feel bad after three hours. So I have to adapt dialysis to me. And that's what I'm doing now.'

Thus, the knowledge Carlos gained about his body in conventional haemodialysis prompted him to find a form of treatment that he could adapt to himself rather than the other way around. So he went for self-care, where the learning process initiated in conventional haemodialysis deepens and intensifies. This is clearly illustrated by the following quote from my interview with Camilla:

> Camilla – When you start to learn how to manage dialysis by yourself, you get to know your body also. Things like – which I didn't get to learn when I had dialysis at the hospital, when they took care of everything – you know, to sense the signals early on, and 'What can my body handle?' and so on. They managed everything, calculated everything. So, you have gained an enormous self-knowledge from managing the treatment by yourself.
>
> Martin – Yes, so now you know how much fluid you can take off and…
>
> Camilla – Exactly, and I know more about my disease, of course. The more you get to learn, the more interested you become in knowing 'How can I

> improve?' And then, through trial and error, you have reached a conclusion that 'this works best for me, to do it in this way, this is what I can manage', and so on. And now I've reached a point where I don't have to weigh myself before dialysis. You've learned to feel approximately how much you've been drinking.

An essential feature of the contemporary ideal of patient-centeredness and an underlying aspect of the development towards increasing the number of patients conducting self-care is the view of the patient as an expert (Lundin 1997; Novas 2006). The idea is that since the sick person is the one who embodies the disease, he or she possesses a unique and invaluable knowledge about it (Juul Nielsen and Grøn 2012). What Carlos's and Camilla's words above illustrate, however, is that such knowledge is not gained as an automatic consequence of falling ill. Rather, its production is the result of a process of learning. There is extensive research to back up this insight (see e.g. Strauss et al. 1984; Charmaz 2000; Barbot 2005). Kathy Charmaz, for example, writes, 'Lessons in chronicity come in small everyday experiences such as difficulty in opening a can, bending over to pick up a newspaper, folding bed sheets, and weeding the garden' (2000, 282).

As I pointed out in the previous chapter, the need for such a process of learning is 'rooted in the structure of human embodiment itself' (Leder 1990b, 12), a structure which allows our attention to flow from, rather than towards, our body, enabling us to orient ourselves towards the tasks at hand rather than towards the bodily movements necessary for performing them. Consequently, our body is ordinarily absent from our attention, and this is true for its surface as well as its depth. Therefore, one cannot take it for granted that the person embodying the body that one wants to know more about possesses the knowledge one seeks. It is not certain that he or she has attended to it in a way that has produced the knowledge sought. But the possibility exists. Since the body we embody is always both subject and object, we may turn our attention towards it as the 'it' which we embody and which embodies us – and we not infrequently do so, 'in the interest of enjoyment, self-monitoring, cultivating sensitivity, satisfying curiosity, or for no particular reason at all' (Leder 1990a, 91). As the previous chapter revealed, however, we are generally not capable of turning our attention towards our inner organs, since they elude 'the self bidirectionally' (Leder 1990a, 56). In the event that we fall ill with kidney failure, then, we do not from the outset possess the means to interpret what is happening to us. We experience bodily dys-appearance and illness but do not immediately know why and how to interpret it. As Toombs (1992), among others, has pointed out, an ill person does have a unique perspective on his or her illness. But gaining a unique knowledge about it requires a process of learning. It cannot, therefore, be assumed that a sick person, or a person in general, may be hired as an expert on his or her own body: first, because the body as he or she ordinarily experience it tends to be absent from his or her attention; second, because he or she initially does not embody a corporeal schema that maps onto his or her ill body.

How, then, do patients learn? And what is the nature of this learning process? In what follows I will attempt to answer these questions by means of an analysis of self-care haemodialysis, a biomedical therapy that in my mind is particularly well suited for this endeavour since it is located at the forefront of the current transformation of medical practice towards viewing patients as experts. As Carlos's words above indicate, and as we saw in the previous chapter, persons with kidney failure gain a lot of knowledge already in conventional haemodialysis about their body as diseased, but this version of haemodialysis offers little opportunity for patients to adapt the treatment to their unique embodiment. For some, as was the case for Carlos, the standardised regime of four hours three times a week might not work at all. In that case, if it is available, they might begin performing self-care. It is on the learning process that commences when they do so that I will focus in the following.

As Camilla clearly states in her account above, self-care orients her not only towards learning to operate the haemodialysis machine but also towards getting to know her own body as sick. It is evident that these two learning processes are deeply intertwined. Learning to manage the treatment – to prepare and operate the machine, insert the needles, and read off and analyse the results – orients patients towards learning about their own body. In fact, the operation of the machine itself requires a deepened knowledge of one's body. Judging from Camilla's words above, however, it does not seem as though it is her proficiency with the machine alone that has produced all the ‘self-knowledge’ she has gained. Rather, it is apparent that self-care, more than simply requiring a deepened bodily knowledge, both opens up an unprecedented possibility for persons with kidney failure to get to know their body and orients them towards this possibility. This is evident when Camilla says, ‘The more you get to learn, the more interested you become in knowing “How can I improve?”’ Rather than automatically providing her with an ‘enormous self-knowledge’, as she describes it, self-care orients her to becoming interested in knowing more.

What makes Camilla so convinced that what she learns about her body through her intimate interaction with the machine actually concerns her particular body? Since the haemodialysis technology is standardised and based on the idea of the human body as universal, might not the numbers and graphs that the machine produces just as well be about any other body or even the human body in general? And why is it that self-care not only just allows but also motivates Camilla to learn more about her body? In order to answer these questions it is necessary to take into account and look closely at the role played by Camilla’s body as she experiences it in this learning process. This body is quite implicit in the quote cited above. Judging from Camilla’s wording, it seems as though the medical body-as-object – which she comes to interact closely with, thanks to her proficiency with the machine – is instrumental to her new ‘self-knowledge’, while her own experiences of the treatment and illness come in second. In reality, however, this is not the case. In fact, the medical body-as-object, the ill body-as-object, and the body-as-subject are implicated to an equal extent in the learning process at work here. When practicing self-care, therefore, Camilla and her fellow self-carers become deeply involved in creating what I have called a ‘sick body’ above.

That this is so is evidenced by Camilla’s reference to the method of trial and error, which, in the context of self-care haemodialysis, consists in attending to the reactions of one’s body to particular treatment settings and subsequently altering these in the hope of avoiding the dys-appearance of one’s ill body-as-object. This is only discernible from reading between the lines of Camilla’s story, but Hans describes this process more explicitly when he tells me how, with the help of the information generated by the machine, he has arrived at a treatment dose that suits him perfectly.

> You write everything down. You check your weight afterwards, your blood pressure afterwards, and the KtV; 'How efficient has the treatment been? How many volume and blood litres have passed through?' and so on. It's to keep track, because then you can find out that, for example, three hours, three times five, that's fifteen hours, that that's not enough. If you increase then – for example, I notice that twenty hours, well that's just perfect – then you can stay there. There are probably those who have more, but, as I've said, you lie down and see how it feels. […] If I do twenty hours, then it's perfect.

This quote illustrates first of all the significance of the information that the machine generates. After the treatment, Hans says, he writes 'everything' down, by which he means all of the information that the machine displays to him. Doing this allows him to 'keep track' of his treatments and to create a kind of treatment history, or treatment line, if you will. Undoubtedly, however, this history would be meaningless if he did not relate it to his experiences of his own body. The key to this insight is the phrase 'you lie down and see how it feels', which Hans utters at the end of the quote. This phrase tells us that keeping track of the quantifiable and functional medical body-as-object is not enough. One also has to attend to the bodily experiences that various treatment regimes give rise to.

But there is more to it than this. In order for Camilla and Hans to really get to know their sick bodies, they have to do the work of creatively imagining and actively constructing a link between their medical body-as-object, on the one hand, and their ill body-as-object and ill body-as-subject, on the other (cf. Cartwright and Alac 2007; Mattinly, Grøn, and Meinert 2011). They have to accept and understand that the body enacted by the haemodialysis machine – which it does by producing numbers and graphs, and emitting sound and light – is closely linked to the body they embody. As we saw in the previous chapter and earlier in this chapter, reaching such an acceptance and understanding is a work haemodialysis patients have to begin with early on in the course of their life with the disease. This is so because, from the beginning, the link between the medical body-as-object, on the one hand, and the ill body-as-object and ill body-as-subject, on the other, is in no way self-evident.

When patients, by means of self-care, begin to deepen their knowledge and practical engagement with the medical body-as-object, this process of learning intensifies further. When they become self-carers, the idea is that they should accomplish an alignment of the treatment with themselves, and the other way around, in order to improve their health. However, it is no more possible to mould the medical body to take the exact shape of one's lived embodiment than it is to shape the body one embodies exactly in line with the standardised and statistical medical body-as-object enacted in haemodialysis. Consequently, it is up to the self-care patient him- or herself to work out ways of accomplishing a functional synthesis. And since what meets the standardised machinery of haemodialysis is a uniquely embodied human being, there can exist no prescribed method for this. Self-care patients such as Camilla and Hans therefore have to be creative and imaginative, for what takes place is in essence a process of creation. Rather than getting to know – learning about – a pre-existing sick body, they create a sick body. This body is not just out there waiting to be found; it is created by the self-care patients through their work of reconciling not only subject with object – not only the body-as-subject with the medical body-as-object and the ill body-as-object – but also object with object – the medical body-as-object with the ill body-as-object (cf. Mol 2002). In creating a synthesis between all three of these aspects of being an embodied person afflicted with kidney failure, haemodialysis patients transform their corporeal schema so that they embody and prereflectively live from a sick body, a body that in each case constitutes a unique mixture of the three aspects mentioned above.

Although Camilla, Hans, and their fellow self-carers are extremely aware of the work they do to manage the treatment and try to adapt it to themselves, what apparently escapes their attention is the way the actions that constitute this work produces a sick body. They all speak of a learning process. And of course they learn, but they learn only by creating. So when Camilla says, 'When you start to learn how to manage dialysis by yourself, you get to know your body also,' the body she refers to is not her body as it has always been, but a sick body that she creatively enacts when she conducts self-care.

Why this process of creation escapes patients' attention may be explained once again by means of Ahmed's theory of repetition. In repeatedly undergoing the treatment, attending to their bodily experiences of it, and reconfiguring the treatment in line with these experiences – what Camilla calls 'trial and error' – the nature of this work eventually disappears from their attention (Ahmed 2006, 56). To use Ahmed's terminology, each treatment session, when analysed by the self-carer, becomes taken for granted as a point, which, when added to other treatment sessions, accumulates into a line, which, in turn, disappears 'from view as the point of view from which "we" emerge' (2006, 15). Thus, the origin of the sick body in creative acts becomes concealed for the self-care patient. It becomes incorporated into the corporeal schema from which he or she orients him- or herself towards the world in general and the treatment and current embodiment in particular. This is why it is experienced as a learning process and Camilla comes to feel that she not only gets to know her body but also gains increased 'self-knowledge'.

What might seem like a paradox here is that the sick body is both absent and present at the same time. In conducting self-care, the patients both proceed from and direct themselves towards their sick body. As suggested by the example I wrote about in chapter 2 of the right hand touching the left hand, it is impossible for an embodied self to touch the touching. 'Insofar as I perceive through an organ, it necessarily recedes from the perceptual field it discloses', as Leder writes (1990a, 14). This also applies to instances where I turn my attention towards my own body: the embodied self that does the perceiving recedes from the perceptual field – its own body – that it discloses. In the example that I am studying here, what recedes from attention is the corporeal schema which, through the repetitive performance of the work of synthesising the medical body-as-object, ill body-as-object, and ill body-as-subject, has created and incorporated a sick body. Rather than being the object which self-care haemodialysis patients direct their attention towards when they try to assess the state of their body, it is by means of this corporeal schema that they attend to their body. What Carlos, Camilla, and Hans have done is to create and incorporate a sick body that affords them the sensorimotor powers to practically and intellectually deal with and understand many of the instances of bodily dys-appearance and medical materialisations of their body that they are faced with. This will become even more apparent later in this chapter and in the next.

What I want to emphasise at present is that the repetition of the treatment that takes place in self-care haemodialysis differs in considerable ways from that which takes place in conventional haemodialysis. Whereas in the conventional version of the treatment patients are forced to subject themselves to the four-hours-three-times-a-week regime and rely on their interaction with the nurses for their habitual incorporation of the medical body-as-object, self-care allows patients to imaginatively and, not least, practically mould the body-as-subject, the ill body-as-object, and the medical body-as-object so that they synthesise as a sick body.

But the sick body is not achieved once and for all. In order to maintain it, self-care patients have to constantly work on themselves and the treatment. Given this, the practical and ideological underpinning of self-care can be viewed as a feature of a more general process identified by sociologist Chris Shilling. According to Shilling, the body is increasingly 'seen as an entity which is in the process of becoming; a *project* which should be worked at and accomplished as part of an *individual's* self-identity' (2003, 4, emphasis in the original). As this quote indicates, the form of body project that Shilling identifies is intimately linked to the project of self-actualisation. It is by actively shaping the malleable entity called the body so that it aligns itself with a desired self that one may realise one's goals and desires (see Giddens 1991). There is thus much to indicate that such body projects can be seen as an essential feature of the activities that the enterprising individuals idealised within neoliberalism engage in. In this context, the body becomes a resource in which a person can invest in order to increase the value of his or her 'human capital' (Foucault 2008, 219). Framed in this manner, self-care may be understood not only as a product of the increasing neoliberalisation of societies, but also as a means whereby patients may come closer to an alignment with the lines of normality (cf. Fioretos 2009; Alftberg and Hansson 2012), which will become increasingly clear as this chapter progresses.

Self-care at the self-care unit

Through the self-care unit in Stockholm runs a wide, T-shaped corridor, along either side of which there are treatment wards. There are also offices, storerooms, a dressing room, a lunchroom, a conference room, and a kitchenette. The entrance to the unit is located at the foot of the vertical axis of the T-shaped corridor. In all, there are eleven treatment wards in the unit. Of these, five are single rooms, intended primarily for patients who are practicing to learn self-care. The remaining six wards contain two or three treatment places. In comparison with Unit 1 and 2 in Stockholm, the self-care unit is thus quite small. In total, only nineteen patients may take their treatment here at the same time, but during my fieldwork at the unit, all treatment places were rarely occupied simultaneously.

As at the conventional units, the treatment is divided into a morning and an afternoon session, but patients have much greater influence over the timing and length of their treatment here. Although there is a general schedule, flexibility is built into the system. Patients may easily change their treatment time by calling the unit. There are roughly three categories of patients. First, there are those who are practicing to learn self-care. These patients perform their treatment primarily on weekday mornings and are always assisted by a nurse. Second, there are the fully trained patients who come to the unit during the time of day when there are assistant nurses on duty. And lastly, there are the patients who have their own entry card, allowing them to take their treatment during all hours of the day. To be included in this third category, one has to display the ability to manage one's own prescription and learn how to disinfect the machine after the treatment.

Generally, self-care patients take shorter and more frequent treatments than patients who undergo conventional haemodialysis, and the total amount of time they spend connected to the machine each week is often longer than the twelve hours that conventional haemodialysis patients spend. The majority undergo between fifteen and twenty hours of dialysis per week, ordinarily divided into five or six treatment sessions. Further, since they do not rely on the assistance of a nurse to start and end their treatment, they have the opportunity to vary its length from day to day.

Consequently, although there is a morning and an afternoon session at the self-care unit, not all patients arrive at the same time. It was clear during my fieldwork at the unit that even the nurses did not always know exactly when the patients would arrive. It was only by repeatedly going on rounds through the T-shaped corridor, popping into a treatment ward here and there, that the nurses – primarily the assistant nurses – would find out who had arrived.

In contrast to the staffing at the conventional units, a large proportion of the staff at the self-care unit is made up of assistant nurses. While the nurses' main tasks are to teach self-care to the new patients and to lead the day-to-day operations, the assistant nurses' primary responsibilities consist in making sure that the fully trained patients successfully start and end their treatments and that all the tests are taken, as well as serving coffee and sandwiches once every treatment session. As a fully trained self-care patient, therefore, one interacts mainly with assistant nurses, but they are not at all as involved in one's treatment as the nurses at the units where conventional haemodialysis is practiced.

Ambiguous space and multiple identities

What follows is in many ways a typical example of what transpires when a self-care patient initiates his or her treatment:

> Stefan has just arrived. He has hung his coat on a hanger in his room and weighed himself. I join him as he pushes a trolley table made of steel up the corridor and into the storeroom. On all four walls of the storeroom are shelves filled with dialysis materials. From these shelves Stefan takes down the things he needs for the treatment. Soon the top shelf of the trolley table is filled with packages of dialysis fluid, bicarbonate, filters, needles, syringes, tubes, and anticoagulants. When he has found everything he needs, he pushes the trolley table out of the storeroom. But before he enters the corridor he stops to get a bag of salt solution from a steel shelf located in the space between the storeroom and the corridor. Then he goes to get his personal belongings. Lining the walls of the corridor at the self-care unit are red cabinets inside which each patient has a shelf with their name on it. Stefan pushes the trolley table to the cabinet that contains his

shelf, and takes out his binder, sheets, blanket, and pillow, and a blue plastic tray on which he keeps his compresses and disinfectants. Placing these things on the bottom shelf of the trolley table, Stefan lets out a moan, which prompts an assistant nurse who is passing by to ask him what is wrong. It turns out that Stefan has a terrible backache. If he wants her to, the nurse tells him, she can come by later with a painkiller for him, an offer that Stefan accepts. When he has gathered all his belongings from the cabinet, Stefan heads off towards his room. His room is located at the beginning of the corridor, while the cabinet is located at its far end, where it splits into a T. On the way back however, Stefan realises that he needs to go to the storeroom again to get some more gauze bandage. Luckily the storeroom is on the way to his room, so he does not have to take a detour. In the storeroom Stefan finds a bandage box, puts it on the trolley table, and heads to his room. When he enters the room, his roommate of the day, Mathias, has just arrived. Mathias has not used a trolley table for his things. Instead he has his arms full of dialysis materials, which he drops on the wooden table on wheels beside his chair. At this point, the assistant nurse enters the room with a pill and a glass of water for Stefan. For a while, it gets quite crowded in the room, which is rectangular and between ten and fifteen square meters large. One enters it through a doorway on one of its short sides. Once inside, one has a sink on one's right, and, along the right long side, the two treatment places, which are placed in such a way that the patients face the left long side when they undergo the treatment. On the wall they face there are two TV sets and a cabinet. Before preparing his machine, Stefan opens the cabinet and takes out a so-called 'dialysis set', which contains three paper towels, a couple of compresses, and a small plastic tub.

Stefan is an experienced self-care patient. He manages the entire procedure by himself. Today, though, the assistant nurse who gave him the painkillers stays around. My first guess is that she wants to assist Stefan with the tasks that may be painful for his back, but then I realise that she wants to learn how Stefan's machine works. As an assistant nurse, she tells me, she has not received training on the type of machine Stefan uses. In fact, there are only two such machines in the entire unit. The reason Stefan uses this particular type is that he often goes to visit his relatives in a town further west, where they only use this model. Consequently, during the entire start-up procedure, Stefan shows the assistant nurse how the machine works.

Since Stefan has a bad back, the nurse offers to help him attach the bag of salt solution to the machine. He accepts the offer and instructs her to hang the bag on the left side of the circle of hooks that extends from the top of the machine. She also helps him attach the bags of dialysis fluid and bicarbonate, whose attachments are located at the foot of the machine, close to the floor. The nurse does not know how to close the hatch around the bicarbonate, however, and has to consult Stefan. When this is done, Stefan starts to 'dress' the machine, which means that he attaches to it the tubes and filter through which the blood will flow during the treatment. He guides the nurse through each step of the procedure and says at one point, 'If I don't get to do it in my order, I forget things.' Stefan works fast, and within a few minutes he has dressed the machine and started the priming process, which is a test procedure during which the machine runs the salt solution through the filter and tubes. Most patients shake and knock the dialysis filter and tubes during the priming process to prevent the formation of air bubbles, but Stefan does not, which surprises the nurse. 'It's a little individual,' he says, though familiar as he was with another type of machine, Stefan used to shake and knock the tubes and filter too. But when he changed machines he noticed that the shaking and knocking often caused a number of error messages, so instead he sits down to do his 'accounting', as he calls the entering of treatment settings into his binder. When he opens the binder, however, he realises that he has forgotten to note the batch numbers of the filter, bicarbonate, and dialysis fluid. Ideally, one should do this before one attaches them to the machine. Luckily the nurse is present to assist him with this. Once this is done, she thanks Stefan for the instructions and gets up to leave. But before she leaves the room, Stefan says that perhaps she should try to the dress the machine herself next time, an offer to which she agrees.

Now the machine is in the midst of the priming process, and Stefan prepares the insertion of the needles. He has already covered one side of his wooden table on wheels with one of the paper towels from the dialysis set. On it he puts the two needles, the syringes, and some patches, which he will use to hold the needles in place. Then he unwraps the two syringes from their plastic wrapping and walks over to the bag of salt solution attached to the dialysis machine. He fills the syringes with salt solution and returns to his chair. Then he prepares the patches. He removes the protective paper from one side of the patches and attaches them to the side of the table. This way he can easily fasten them around the tubes extending from the needles using only one hand. Then he unwraps the needles and puts a pile of compresses in the plastic tub. Since Stefan's treatment place is close to the windows he can store some of his things on the windowsill. Here he has put his blue plastic tray, from which he takes a bottle of disinfectant. He opens the bottle and pours some of it over the compresses in the plastic tub. Then he pulls the wooden table closer, puts his arm on the table and disinfects it using the compresses. It looks like he uses a fair amount of force. I get the impression that he takes the opportunity to check the position of his graft. Then he takes a needle from the wooden table and, without even the slightest hesitation or time for consideration, inserts it into his arm, at one end of his graft. He spins the needle a little from side to side when he inserts it, but he does not flinch. He seems neither to feel any pain nor to worry about the success of the insertion. When the needle is in place, he fixes it there with some patches. He holds the patch with one hand and removes the remaining piece of protective paper from it with the fingers of the arm he has just pierced. It looks fiddly. Lastly, he 'flushes' the needle, which means that he attaches one of the syringes to the tube that extends from the needle, draws a little blood into it, and then injects it into his arm together with the salt solution. He repeats this procedure with the second needle, which he inserts a little further down the forearm. However, before he has finished fixing and flushing this needle, the dialysis machine signals that the priming is done. 'Good timing,' I say, which proves to be wrong since the machine automatically starts the dialysis process when it has finished priming. Stefan is now forced to 'fool the machine', as he puts it. Ordinarily he is slightly ahead of the machine and has already connected himself to it when the dialysis process begins. But today he has to fool the machine by allowing the treatment program to start but setting the pump at zero. This way, the machine stands still while he finishes his work with the needles.

When he has flushed both needles he rises and unscrews the tube that is connected to the bag of salt solution, all the while holding the syringes that are still connected to the needles between the fingers of his left hand. Then he removes one of the syringes and connects the tube extending from the needle to the tube that was attached to the bag of salt solution. He repeats this procedure with the other needle, connecting it to a tube attached to the bag where the salt solution ends up after the priming. Stefan is now connected to the machine, and he injects an anticoagulant into his blood, which is now starting to travel through the tubes into the machine. The machine gives off a sound and Stefan touches its touch screen several times. The light on top of the machine turns red and Stefan says, 'Now I'm up and running.'

> There are, however, a couple of things left to do. For instance, he needs to secure the tubes that now extend from his arm, which he does by tying some gauze bandage around his wrist and around the tubes themselves. This, too, looks tricky. Again, Stefan has to make use of the fingers of his left hand, which he bends back to assist the right hand in tying the knot. Then he turns the filter upside down, allowing the blood to flow through it in the right direction, after which he sits down in his chair to do some more accounting. Lastly, he measures his blood pressure, which turns out to be slightly high. It has been so lately, and Stefan says that it might be an indication that he does not remove enough fluid. But, he tells me, he is a little afraid to adjust his weight, since such adjustments may cause cramps or drastic blood pressure drops.

As this episode illustrates, self-care haemodialysis orients patients to become more mobile and extend their movements into a larger number of spaces than conventional haemodialysis does. While conventional haemodialysis patients generally only pass through the waiting room, corridor, and dressing room on their rather straight way to the treatment ward, at the self-care unit, patients go up and down the corridor, into the storeroom, up to their cabinet, down to the scale, into the kitchenette, back again to their ward, and perhaps end their treatment by heading out into the corridor to measure their blood pressure. Further, unlike patients who undergo conventional haemodialysis, whose mobility becomes radically reduced as soon as they reach their treatment place, self-care patients extend their mobility to include also the space around the haemodialysis machine. They dress, prime, and program the machine, arrange their things on their wooden table, puncture their arm, and connect themselves to the machine. When Stefan prepares to start his treatment, he moves between the machine, chair, and cabinet located opposite his treatment place. Even after he has inserted the needles, he gets up from his chair and unscrews the two tubes through which his blood will soon flow, all the while holding the syringes attached to his arm between his fingers.

Self-care patients are not only more mobile than conventional haemodialysis patients. The temporality of their movements is also more varied. At the self-care unit, patients may to a greater extent do things in a varying order. Stefan, for instance, weighs himself before he gathers his dialysis materials. Bengt, on the other hand, goes to the scale while the machine is priming. But the temporality of their movements varies more than this. One morning, when I follow Bengt as he has just primed his machine and headed out to the kitchenette, Walter, another patient, has only just arrived. But rather than feeling any pressure to immediately initiate his treatment, Walter sits down at the kitchenette table, calmly eating his homemade egg sandwiches.

To a certain extent, patients' temporalities differ at the conventional units too, but there, only a few minutes separate their movements, movements that are moreover oriented in line with strict institutional lines. By contrast, the fully trained self-care patients only have to take into account some outer temporal boundaries – unless they have their own entry card, an object that blurs these boundaries too. If one does not have an entry card, there are two temporal rules to follow. First, one may take one's treatment only when there are assistant nurses on duty. Second, one must always start and end one's treatment within the temporal boundaries of each shift.

The main purposes of the existence of such temporal flexibility is to allow patients to adapt the treatment to their personal lives – to enable them to keep working, studying, and/or living functioning family lives while undergoing haemodialysis – and to improve their health by enabling them to adjust the treatment to their bodies. Interestingly, this flexibility creates unique possibilities for the patient-as-person to emerge in the treatment practice. While at conventional haemodialysis units, patients extend as persons through the repetition of the standardised institutional lines that they follow and the close relationship that they develop with the nurses, at the self-care unit, patients extend as persons primarily through the personal ways in which they manage their own treatment. That Stefan has developed his own way of doing things was evident when, in the excerpt from my field notes above, he said, 'If I don't get to do it in my order, I forget things.' Similarly, unlike most of his fellow patients, Bengt connects himself simultaneously to both of the tubes extending from the machine, while Hans, rather than applying pressure to the areas where the needles have been inserted with his hands, as it is usually done, uses his chin and a couple of compresses previously prepared with tape to stop his bleeding after the treatment.

Since 'space acquires "direction" through how bodies inhabit it' (Ahmed 2006, 12), the flexibility of self-care haemodialysis not only personalises patienthood but also shapes the sheer spatiality of the unit. While in conventional haemodialysis, patients become aligned with the institutional lines that result from the constant repetition of the strictly regulated spatiotemporality of the treatment, in being able not only to develop their own way of doing things, but also to influence when they do them, self-care patients leave their personal marks in the space of the unit to a greater extent. 'That's the advantage [of being] here compared to an institution,' Hans says, referring to the fact that he may take the treatment during all hours of the day. This statement indicates the way in which the self-care patients' orientations shape what the unit becomes, or at least what it does not become. It was evident in my observations and conversations with patients and medical practitioners at the self-care unit that, as a consequence of the patients' largely personalised orientations, the unit ceased to be an 'institution' or a 'hospital'. Patients as well as nurses often contrasted the spatiality of the self-care unit with that of conventional haemodialysis units by referring to the latter as a 'hospital' or an 'institution' and the practice taking place there as 'institutional dialysis'. Less clear, however, was what kind of space the self-care unit was. When I accompanied Bengt as he started his treatment, I asked his roommate Johnny if he had ever had dialysis at home, to which he answered, 'No, only at hospitals and here.' When the conversation continued, Bengt and Johnny agreed that 'it's the same stuff here as at home', to which assistant nurse Ritva added that the unit is really 'homey'. And before he got ready to insert the needles, Bengt ended the conversation by exclaiming jokingly, 'Before you know it, you're married to the staff here.'

This conversation not only shows that self-care patients, just like their peers in conventional haemodialysis, develop rather personal relationships with the nurses. It also illustrates the way in which the practice that takes place here enacts the spatiality of the unit as an indefinite 'here'. When Johnny says that he has only had dialysis 'at hospitals and here', he makes it clear that the self-care unit is something other than the hospital units where conventional haemodialysis takes place. Perhaps, then – if taking the treatment 'here' or at home 'is the same stuff' – the unit is more similar to a home. This at least is what Ritva indicates in choosing the word 'homey' to describe it. Even so, the self-care unit is not a home; it is at most only homelike. Thus the ambiguity persists, and during all my days at the self-care unit, this ambiguity haunts me somewhat. So on my last day of observations, I ask Margret, who is one of the two nurses who teaches self-care to patients, what, in her opinion, the self-care unit is. 'What are we really?' she asks herself, and then continues, 'We are not really a hospital, but we are within the walls of a hospital.'

Here, rather than being resolved, matters become even more complicated. What Margret tries to tell me is that, even though the self-care unit is not located at a hospital, its practice formally belongs to one. Thus, when she says 'we are within the walls of a hospital', she is referring to the fact that the care practice enacted at the self-care unit is governed by a hospital, not that it is physically part of one. The unit is thus formally and not spatially within the walls of a hospital. But what does this make it? Judging from Margret's words above, this is difficult to determine. In her view, the self-care unit both is and is not a hospital unit. Consequently, the ambiguity persists, and when I leave the self-care unit, my lasting impression is that it is easier to say what the unit is not than what it is.

Why this is the case might become clearer if we return to the orientations of the patients at the self-care unit. As Ahmed points out, orientations not only direct space, but they also shape us as embodied beings. Our orientations are not external to who we are, but intrinsic to the nature of our being-in-the-world. This entwinement of oriented space and oriented embodiment suggests that the question of where we are can never be separated from the question of who we are (Merleau-Ponty 2002, 291–293; Ahmed 2006, 65–66). Therefore, it is not strange that Margret answers my question about the nature of the space of the self-care unit by asking herself 'What are *we* really?' and then establishing that 'We are not really a hospital, but we are within the walls of a hospital.' What Margret seems to say here is that 'we are not patients and nurses in a way that makes the unit a hospital, but we are seen as nurses and patients by the hospital that governs our activities'. Thus, since the identities of the persons who reside at the self-care unit are ambiguous, so is the unit itself.

But in what ways are the identities ambiguous? I have argued above that the care practiced at the self-care unit, to a greater extent than that at conventional haemodialysis units, personalises patients. The temporal flexibility of the care practice as well as the extensive mobility and activity of patients allow them to extend as persons into many of the unit's spaces and during many of the treatment's phases. But, as Margret poignantly points out, they are within the walls of a hospital, a hospital that defines them as patients and nurses. Consequently, the persons with kidney failure who take their treatment at the self-care unit both belong to the patient category and extend as persons into the space of the unit – which to a lesser extent was the case also at the conventional units. But more than this, and unlike their peers in conventional haemodialysis, the self-carers also transform themselves into some kind of medical practitioners, or perhaps even nurses. In orienting themselves in line with the flexible yet institutional lines of self-care haemodialysis, patients become actively engaged with the medical objects that surround them in ways very similar to medical practitioners. From a phenomenological point of view, our meaningful inhabitance of the world relies not only on what objects we are oriented towards but also on the ways in which we are oriented towards them. How we shape and are shaped by the objects around us depends on the way we arrive at them and what we do with them. Our intentional movements in relation to an object are part of its meaning just as much as the meaning of an object affects what we become (Merleau-Ponty 2002, 294: Ahmed 2006, 40). Consequently, one could claim that in doing what nurses usually do, with things nurses usually use, patients become nurses.

However, despite its persuasive logic, this statement is not entirely true, since patients, unlike nurses, embody an illness, care only for themselves, lack a formal medical education, and are not employed by the unit. But as a result of their skilful and independent handling of the dialysis materials, they do transcend their patienthood, and do to some extent take on the role of a nurse. Thus, the care practiced at the self-care unit not only personalises patienthood but also professionalises it. Persons with kidney failure who come here to take their treatment are to a varying degree simultaneously patients, persons, and medical professionals. In accordance with the ideal of the new patient, they extend into the unit as persons who expertly manage their own bodily dysfunction. But it is clear that their embodiment of these multiple roles makes their identity, and, as a result, also their relation to the nurses, ambiguous. Self-care patients simultaneously 'see us all as colleagues', as assistant nurse Petra puts it, and become so close to the nurses that 'before you know it, you're married to the staff here', as Bengt jokingly exclaims, all the while residing in an environment that defines them as patients and nurses.

Interestingly, it is primarily the nurses who describe this ambiguity as problematic. Judging from my empirical material, this might be because the nurses are the ones who have most to lose from the dissolution of the clear roles that the practice of self-care entails. While the patients gain knowledge and access to additional spaces and become able to influence the structure of their own treatment, the nurses lose the stable ground on which their professionalism and authority ordinarily rests. This was evident, for example, in my conversations with assistant nurses Anita and Petra, in which they told me about patients who view themselves and are viewed by the nurses as colleagues who may enter the staff lunchroom unannounced or as friends one may go to parties with. This clearly attests to the way in which the nurses' transformed and multiple relationships with the patients risk reducing and obscuring the professionalism and authority commonly associated with their role. Anita is careful to point out, however, that as long as some boundaries are retained, the altered patient–nurse relationship may be an asset. In her view, if, as a nurse, one manages to balance the line between personal and private, a unity between nurses and patients may be created which, if properly tended, strengthens patients' confidence in nurses' professionalism. Thus, if as a nurse one is willing and capable of altering one's role, there is much to gain from the multiplied and ambiguous orientations of patients at the self-care unit.

Activity as a fundamental component of normality

As the previous section revealed, self-care haemodialysis orients patients towards becoming more mobile and towards extending their movements into more spaces than conventional haemodialysis does. This extended mobility is a consequence of the fact that self-care patients manage their own treatment. Unlike their fellow patients in the conventional version of the treatment, they prepare, start, monitor, and terminate their treatment. In other words, they become actively engaged with their own body and the technologies they rely on for their survival in ways that conventional patients do not. As we shall see, this activity stands out as the most fundamental condition for the processes of normalisation that the self-carers contend have ensued since they started managing the treatment by themselves.

This is evident, for instance, in the following quote, in which Camilla compares self-care to conventional haemodialysis:

> Well, at the first place [conventional unit], you didn't do anything yourself. You lay on a bed and everyone did everything for you, inserted the needles and took care of the machine and so on. I don't know, but it becomes more dramatic when it takes three people to do it. Now, when I do it by myself, it's not such a big deal anymore. Now it's just something that I do a couple of hours a day.

In this quote, the doing – the activity – emerges as an essential condition for Camilla's capability of de-exceptionalising the treatment, of making her dependence on dialysis as insignificant as possible (Amelang et al. 2011). It is by emphasising her activity – by describing haemodialysis as something she just does, rather than something that is done to her by others – that Camilla de-dramatises the treatment. But this de-exceptionalisation is not entirely Camilla's own doing. As a self-care patient, she has no other choice but to be active. The treatment practice forces it upon her. At the same time, however, this enables her to describe herself as an active self-carer in little need of any interventions from nurses or other medical professionals. Thus, self-care not only activates Camilla but also frees her from her dependence on others, and this independence is to a great extent a product of her activity. Because undergoing the treatment is necessary for Camilla's survival, it has to be performed, and if she does not manage it by herself, she will inevitably be dependent on someone else to do it. Therefore, in the case of haemodialysis – and many other medical treatments – gaining independence presupposes that one actively takes charge of one's own treatment.

This is evident also in these words, spoken by Carlos: 'When you go to Unit 2, someone else takes care of you. But when you go to the other place [the self-care unit], no one else takes care of you. It's me who takes care of myself. It's me and the machine, no one else, only if I need help. But I'm in charge.' Although Carlos has just recently moved to the self-care unit when we meet, he has already discovered some of the benefits associated with being actively engaged with the treatment. Rather than being cared for, he takes care of himself, which not only entails increased independence but also means that the intermediary link between him and the machine vanishes. Self-care haemodialysis leaves Carlos alone with, and puts him in charge of, the machine, a relationship that is facilitated by and requires his active engagement with it. The activity that self-care entails thus transforms the machine from an uncharted territory controlled by the nurses to a known object that not only comes under patients' control but also begins to function as an 'orientation device' by means of which patients may extend and orient themselves as persons in the context of the treatment (Ahmed 2006, 3).

As Mol (2008) shows, the idea that we can and should be in charge of and control the technologies we use constitutes a powerful neoliberal ideal (see also Hayles 1999). From a phenomenological point of view, however, this idea is to a large extent illusory. The fact that the persons conducting self-care haemodialysis create and cultivate a sick body is a convincing indication of this. This body is simultaneously medical and experiential, which means that when a self-carer controls the workings of the treatment technology, he or she does so by means of an embodied knowledge that to a large extent originates from the technology itself. Moreover, the technology does not just generate this knowledge. It also orients self-care patients to become interested in extending their knowledge.

These findings are akin to Don Ihde's characterisation of technologies as 'non-neutral' material instruments that possess the power to alter or provide us with new '*trajectories of inclination*' (1993, 116, 128, emphasis in the original; see also Mol 2008; Reiser 2009, 187–188). Technologies are non-neutral, Ihde argues, because they are never just added to a world. Rather, when they enter human use, they transform the world as well as their users. By foregrounding some objects rather than others and affording us new modes of interpretation, technologies affect our perception, and in so doing alter not only our access to the world but also our intentions. And the opposite is true as well. When technologies enter into human use, they do not remain unaffected by this use (cf. Mattingly, Grøn, and Meinert 2011). By applying the concept of 'the designer fallacy', Ihde shows how technologies more often than not get used in ways that exceed what was originally intended (1993, 111–116). The telephone, for instance, was originally intended for persons with hearing impairments, offering them a way to amplify sound. But as we all know, the telephone would later become an invaluable mode of communication for almost all citizens of the world. Consequently, the entrance of the telephone into human use caused a transformation of the technology itself. But the telephone also transformed us, since it altered our conception of the meaning of communication as such. With a telephone in our hand we intend new things. This is true also for the haemodialysis machine. As we saw in a previous section, when Camilla learned to operate the machine by herself, she noticed how her intentions became oriented towards wanting to know more about her own body.

With this in mind, it would be a mistake to claim that we can and should control technologies. A more fitting way to put it would be: 'I am used as much as I use any technology', as Ihde asserts (1993, 116). But in light of this, what does it mean to feel that one is in charge of a technology as Carlos does? Without depriving Carlos of the control he actually exercises over the machine, one can contend that the technology, in this case the haemodialysis machine, provides a frame and meaning-content for the controlling activities that he performs. By foregrounding particular parts of his body and the function and health of these parts, the machine orients his perception in a way that gives him a particular view of himself and the world around him, making him able, as we have seen in the examples of Camilla and Hans, to understand himself through the technology. But this is not a closed process. By being open to manipulation in various ways, the machine gives Carlos the opportunity to alter not only his own bodily state but also the workings of the machine itself. In doing so, he imaginatively and creatively transforms the technology to become aligned with his body, at least to the extent in which this is possible.

What is important to keep in mind here is, once again, the cultural context in which this transformation takes place. As Ahmed points out, orientations simultaneously rely on and open up normative and moral worlds as an effect of their repetition (2006, 158). In this way they determine not only what objects we come in contact with, but also how we come in contact with them. Since our intentional movements towards an object are an intrinsic part of its meaning, the nature of our encounter with a particular object shapes the object itself as well as us as embodied beings (Merleau-Ponty 2002, 157; Ahmed 2006, 61–63). Consequently, when haemodialysis patients begin to orient themselves towards the haemodialysis machine with the intention to operate it, the particular world in which this encounter takes place affects the nature of this orientation. In the cases we are concerned with here, the encounter takes place in a worldly context that promotes self-care and praises a person's ability to exercise control over technologies. A person who conducts self-care in such a context will therefore be oriented in a way that makes him or her pay more attention to and put more emphasis on the actual controlling actions that he or she performs, rather than acknowledging the fact that the knowledge required for performing these actions originates to a large extent from the technology itself. In a context that promotes self-care, control is thus foregrounded, while dependence – or rather the mutual dependence of body and technology – is relegated to the background.

I began this section with the claim that activity, in the context of self-care, not only constitutes a pervasive norm in itself but also functions as a fundamental condition for patients' ability to align themselves with other pervasive norms. What I claimed was essentially that activity, just like freedom, is simultaneously normative and normalising. This claim has subsequently remained mostly implicit. But I believe I have illustrated quite convincingly that the self-carers' alignment with powerful norms such as independence and control relies heavily on their active engagement with the treatment technologies. It is when they go from being acted upon by the nurses to managing the treatment by themselves that it becomes possible for them to describe themselves as independent from the nurses, as in control of their situation, and as capable of knowledgably adapting the treatment to their sick body.

Why, then, does activity have this fundamental role? As I argued in the previous chapter, an answer to this question can be sought, at least partially, within phenomenology. For Merleau-Ponty, 'Consciousness is in the first place not a matter of "I think that" but of "I can"' (2002, 159). It is by being practically engaged with the world that we give meaning to the objects around us, as well as to ourselves, he argues. For this to be so, our body schema has to remain prereflective, since if we were constantly thematising the meaning-giving actions that we perform, we would lose our connection to the world as well as the unity of our body schema (Leder 1990a, 15; Malmqvist and Zeiler 2010, 137). When we become the objects of other persons' actions, therefore – which Carlos, Camilla, and Hans argue was the case at the conventional haemodialysis units where their treatment careers began – our linkage to the world is, if not completely lost, at least diminished (cf. Beckman 2009; Ehn and Löfgren 2010). As a consequence, our meaningful inhabitance of the world relies on our practical engagement with it. It is through inhabiting the world in an active way, rather than becoming the objects of other persons' actions, that we are able to find out who we are and leave our sometimes quite personal marks on our surroundings, as Carlos, Camilla, and Hans do.

Although I do not doubt the validity of this explanation, I believe that in order to understand its significance in the context of health care as it is practiced at the moment in Latvia and Sweden, it is necessary to contextualise it. I have already mentioned the imperative of activity that Rose argues has gained force in neoliberalism, in which activity becomes equated with the enterprising actions performed by a person engaged in his or her own self-actualisation. In this context, self-care emerges as a way in which sick persons, despite suffering from an illness, may regain an orientation towards an actualisation of themselves (cf. Shilling 2003; Rose

2007). By becoming experts on their own health, working on their body as an ongoing project and taking control of their treatment, sick persons can expect to become capable of caring for themselves in a way that puts their own unique goals and desires at centre stage (cf. Juul Nielsen and Grøn 2012). But the premise of this is activity. It is only by being active in relation to their treatment and their body that patients may escape their dependence on caregivers, regain a sense of control over their situation, and begin to adapt the treatment to their own unique needs and desires. Thus, in order to align themselves with pervasive neoliberal ideals such as autonomy, responsibility, and control, becoming active in the neoliberal sense of the term is essential.

So when Hans, Camilla, and Carlos learn to manage haemodialysis by themselves, they both reinforce their practical engagement with the world and align themselves with the particular world that idealises activity. These two processes are of course deeply interrelated. The world that Hans, Camilla, and Carlos inhabit is always already the world that idealises activity. But if it were not for their practical engagement with this world, for their actual, embodied activities, an alignment with this ideal would be unthinkable. One should keep in mind, moreover, that the imperative of activity prescribes only certain activities. One may therefore very well be actively and practically engaged in the world without being perceived as such.

The risky uneventfulness

Irrespective of the form of haemodialysis a person undergoes, inactivity, or perhaps, rather, uneventfulness is always an inherent feature of the treatment. During the major part of a haemodialysis session nothing in particular happens. After the treatment has been initiated and before it is terminated, several hours pass during which the patients lie on their beds or sit in their chairs. Since they are connected to a haemodialysis machine they cannot do anything but lie or sit. The treatment immobilises them, tying them to a particular and highly delimited place for a given amount of time. During this time, the main actor is the haemodialysis machine, and if everything runs smoothly, little attention needs to be directed towards it. The majority of the time patients spend connected to the machine is essentially uneventful. From the point of view of the medical personnel, uneventfulness is a good thing since it indicates that the treatments are proceeding without problems. From the point of view of patients, however, it is a risky business, which the following account by Yevgeniy illustrates:

> I think the most important thing is not to think about the time. Because when you think about the time, when you look at your watch regularly, then the four hours seem pretty long. It's better to occupy your mind, to read, to listen to the radio, and those who can sleep, sleep.

Yevgeniy's words clearly demonstrate the threat posed by the uneventfulness characterising the treatment. Since nothing in particular happens, the risk is imminent that one's attention is directed towards the passage of time itself, thereby making it pass even more slowly. But why is this a problem? Why is this the most important thing to avoid according to Yevgeniy? To answer these questions, Liouba's words may be helpful. She says:

> The most important thing is for time to pass as fast as possible. We read books, watch TV, and speak here… It's difficult to lie in bed; it's hard… The machine works without interruption, and the cleansing of the blood proceeds so that I can feel better.

Just like Yevgeniy, Liouba emphasises the importance of ensuring a steady passage of time. But she provides us with some clues about why this is important. It is difficult to undergo the treatment, she says, thereby echoing the absolute majority of the patients I have talked with. Haemodialysis is for the most part and for most patients a draining, demanding, and sometimes painful treatment. Many characterise it as a 'necessary evil', as something they know they have to undergo but would opt out of if there were a choice.[58] During a haemodialysis session, therefore, they tend to look forward to its end, wanting the time to pass as fast as possible.

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[58] Cf. the section entitled 'Acceptance' in the previous chapter.

But there is more to it than this. Clues to what this might be can be found in the methods Yevgeniy and Liouba advance for counteracting the slow passage of time. Yevgeniy suggests that one occupies one's mind by reading, listening to the radio, or sleeping, and Liouba associates the fast passage of time with reading, watching TV, and talking. Essentially, then, what they suggest are activities. The way to counteract the slow passage of time, they argue, is to be active. This is logical since it is essentially the uneventfulness of the treatment that causes the time to pass more slowly. Or rather, the uneventfulness brings forth the passage of time itself, which makes it pass more slowly. So here, once again, we are dealing with the existentially and normatively charged imperative of activity.

If we begin with the existential dimension, which I have discussed in this and the previous chapter, we can see that the passivity which haemodialysis forces upon its patients risks inhibiting their practical and prereflective extension into the world. In being installed at a particular place for a particular time, with little opportunity to engage themselves practically with their surroundings, the patients risk losing their orientation in the world; they risk becoming disoriented. As Yevgeniy so poignantly points out, the primary risk is that one will start thinking about the time itself, thereby slowing it down.[59] This has to do, on the one hand, with the thematisation of time inherent to the practice of haemodialysis itself. Patients not only long for the four hours to end, but time is also constantly thematised on the displays of the haemodialysis machines and in the evaluative conversations nurses and patients tend to engage in at the end of a treatment session, for example. On the other hand, the risk of thematising the time itself has to do with the way the uneventfulness causes it to emerge. As ethnologists Ehn and Löfgren have argued in their exploration of the phenomenon of waiting, 'waiting draws attention to the passing of time. Without inherent content of its own, the time spent waiting passes more slowly because one is so preoccupied with the clock' (2010, 21). In such instances, instead of being prereflectively lived, time emerges as that which

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[59] As we saw in the previous chapter, passivity is linked to thinking in general. When one is passive, the participants argue, there is a risk of meaningless and harmful thoughts emerging.

is attended to, which may prevent a person from prereflectively and practically extending into the world.

There is much to indicate that a thematisation of time may have even graver consequences for persons who, like Yevgeniy and Liouba, suffer from a chronic and life-threatening disease and undergo invasive medical treatments. As their words indicate, time during a haemodialysis session is deeply intertwined with the space in which it is spent and the events, or rather the uneventfulness, that takes place here. If and when they thematise time in this context, therefore, they are witnessing the deceleration not of a pure time, but a time deeply coloured by their dependence on haemodialysis and their embodiment of a chronic and life-threatening disease. This was particularly evident in Liouba's account, where she linked the importance of ensuring a steady passage of time with her dependence on the workings of the haemodialysis machine. As her words indicated, the machine and the diseased body it sustains constitute a constant background presence during the session, one that persistently enacts her diseased body and her dependence on the treatment. As a consequence, in the event that she fails to activate herself, the risk is that this constant enactment emerges from the background, forcing her to thematise the fragile state she is in.[60] As we saw in the previous chapter, persons undergoing haemodialysis invest a lot of energy in avoiding such thematisations, a challenge that the uneventfulness of the treatment makes particularly difficult. The solution, as both Yevgeniy and Liouba point out, is to keep oneself occupied, which we shall see below is not always easy.

Moving on now to the normative dimension of the dichotomy between activity and passivity evident here, it is reasonable to believe that Yevgeniy and Liouba find the uneventfulness characterising the major part of a haemodialysis session difficult to handle also because it prevents them from aligning themselves with the lines emanating from the imperative of activity. Their desire to accomplish such an alignment quite likely contributes to their emphasis on the activities that they do engage in during the treatment. As we have seen previously, being able to describe oneself as

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[60] As Ahmed has pointed out, such emergences of the background not infrequently cause disorientation (2006, 106).

active brings one closer to normality. But as Ehn and Löfgren have pointed out, 'Western modernity developed not only new forms of impatience but also certain ways of virtuous patience' (2010, 29). Among the emerging European middle class in the nineteenth century, patience was advanced as an ideal trait to be cultivated. Children, for example, were to be taught from an early age the art of 'deferred gratification' (Ehn and Löfgren 2010, 32–33).

In this context, one can view Yevgeniy's and Liouba's emphasis on the difficulty of managing the uneventfulness of the treatment and their strategies to manage it as an attempt to align themselves with this ideal of patience. It is then not their activities per se that are the focal point but their ability to responsibly and autonomously endure the hours they spend connected to the machine. That patience is a relevant concept here is indicated by the fact that the word 'patience' is semantically linked to the word 'patient'. From this perspective, it is not so far-fetched to claim that, just by assuming the role of patient, Yevgeniy and Liouba are expected to be able to exercise patience (cf. Bremer 2011).

The two normative landscapes presented here – the imperative of activity and the imperative of patience – are not just often deeply intertwined themselves; they are also inseparable from the existential dimension described above. The mutual dependence of activity and patience becomes evident when the importance of activating oneself during the uneventful part of the treatment, which Yevgeniy and Liouba emphasised above, is paired with the patience required for finding suitable things to do. It is not easy, many of the participants point out, to find activities that do not themselves orient one's attention towards the fragile state of one's body. Veronica wishes she could read more during haemodialysis, but she finds it hard to concentrate. Either she does not understand what she is reading or she falls asleep. Marianne, who manages the treatment by herself in her home, describes it similarly: 'There's no point in reading,' she says, 'since my concentration is poor.'

Akin to Sartre's example, which I described in chapter 2, of a person with a headache reading late at night, Veronica and Marianne experience their illness, or perhaps rather the side effects of the treatment, in the very act of reading. To them, what emerges as a lack of concentration in the act of reading, however, is not some indistinct prereflective experience of discomfort – which constitutes the first stage in Svenaeus's (2009) and Toombs's (1992) models of falling ill – but an experience that they immediately and prereflectively link to their embodiment of kidney failure and their dependence on haemodialysis, thereby adding to the synthesised sick body that they have already created to varying extents, through their repeated bodily engagement with the treatment technologies and their use of the three interrelated modes of coping. But despite this capability of synthesising, the problem remains. What should one do during the treatment? The challenge, according to Veronica, is to find an activity that passes the time but is undemanding enough not to provoke bodily dys-appearances.

For Veronica this was difficult, but after a while she discovered Sudoku. Sudoku, she tells me, demands her attention just enough. It orients her away from thematising the passage of time itself but is not so demanding as to cause her body to dys-appear, which reading tends to do. Marianne has found that talking on the telephone or watching a movie are suitable activities during the treatment; both ensure a steady passage of time without being too demanding. In summary, then, one can contend that in order to be active during haemodialysis, patients have to patiently try out a whole range of activities to find one by means of which they may orient themselves away from, rather than towards, their fragile embodied state.

The reverse is also true: in order to be patient, one has to be able to engage in at least some activity. Marianne's ability to be active during the treatment depends not just on her, but also on the availability of others willing to engage in phone conversations, or on the movies and other programmes on TV. Sometimes, she tells me, 'my husband might not be home, nothing happens, nothing good on TV, no one to call, no one calls, then it's just boring.'

Drawing on Heidegger, Norwegian philosopher Lars Fr. H. Svendsen (2003) uses the concept of unhomelikeness to describe the potential of boredom to throw us into a state of deep existential disorientation. Akin to Svenaeus's characterisation of illness, Svendsen's view of boredom, at least in its deep form, is as an attunement that restricts our extension into the world, that disrupts our meaningful intertwinement with the objects and others around us. Svendsen distinguishes between two forms of boredom: shallow or situational boredom and deep boredom. In its situational form, it has an object; the person who is feeling bored knows what bores him or her. In deep boredom, it is not clear what it is that is boring; one's whole situation is characterised by emptiness and meaninglessness. It is particularly this form of boredom that may cause an unhomelike being-in-the-world, Svendsen contends (2003, 147–158). In the quote above, Marianne's boredom clearly has an object. It is the treatment that bores her. In being aware of the object of her boredom, she knows that if she just patiently awaits the end of the treatment it will disappear. Her boredom, then, is of the situational kind described by Svendsen, and this kind can be managed by exercising patience.

But can we be sure that the boredom Marianne talks about above is always of this kind? As I argued above, the time patients spend connected to the haemodialysis machine cannot be separated from its spatial and corporeal dimensions. In thematising the time, patients therefore risk thematising the fragility of their existence as well – that is, their embodiment of a chronic and life-threatening disease and their dependence on life-sustaining medical treatments. The boredom Marianne experiences when she is unable to activate herself during the treatment may thus turn into the deeper kind. In being unable to fill the hours she spends connected to the machine with activities, the boredom may extend to include her entire existence, by spurring the emergence to her attention of her fragile state. Patience is then no longer an effective counter-strategy, since there is no end to patiently await, only the perpetual presence in one's life of renal replacement therapies and an incurable disease.

This is even more evident in my conversation with Bengt. When I ask him how he feels about spending so much time in a hospital environment, he tells me:

> I think you should be extremely happy that you get to come here [the unit] and undergo this [haemodialysis] and then return home knowing that 'now I will live a couple of days more.' It's actually as simple as that. It's boring [laughs a little], but I think that, since you know that if you didn't do this you wouldn't exist, you think a little bit differently.

Even though the main idea Bengt wants to put across in this account is the senselessness of giving into feelings of boredom – since the treatment enables him to live on, the boredom it elicits is pointless – it also demonstrates the intimate connection between boredom and deeply existential matters. The very presence of the word 'boredom' in the middle of an account about life and death illustrates its force. To escape boredom, Bengt seems to say, one has to take a step back and thematise the underlying meaning of the treatment, which is to enable one's continued existence. But perhaps there is no need to take a step back. Perhaps the boredom one experiences has already caused the fragility of one's existence to emerge.

Like Veronica, Bengt has found that Sudoku is a fitting activity to occupy himself with during the treatment. It passes the time, he tells me. But he also watches TV and reads newspapers. But 'sometimes', he says, 'I can't do the simplest goddamn thing.' This is due, he contends, both to the temporary drowsiness and lack of energy that occurs after a while during almost every haemodialysis session and to the long-term damage that the treatment causes to his body in general and his brain in particular. To overcome the temporary drowsiness and lack of energy, it is often enough to ingest a protein drink, he tells me. The long-term effects, however, are impossible to avoid. Bengt's main concern is the damage haemodialysis does to his brain. His theory is that, during the treatment, tiny air bubbles are formed in his bloodstream, bubbles that enter his body and damage his brain. This is not just frightening, he says, but also occasionally prevents him from doing anything at all during the treatment, thus making it boring.

There is thus an intimate interplay between the fragility of Bengt's existence and his feelings of boredom. The boredom he experiences is both an effect of this fragility – in that it tends to prevent him from doing something during the treatment – and a cause of its emergence – in that it forces him to contemplate the fact that haemodialysis paradoxically both enables and limits his embodied presence in and extension into the world. There is a form of circular movement at work here: in doing permanent damage to Bengt's body, haemodialysis occasionally prevents him from activating himself during the treatment, and this, in turn, provokes a form of boredom that forces him to contemplate the fragility of his existence. As a consequence, in his struggle to combat boredom by reassuring himself of the life-sustaining capacity of haemodialysis, there is no need to take a step back. The boredom he experiences has already brought him to this existential level. Rather than sheer patience, therefore, Bengt must mobilise the most fundamental reason behind the treatment's presence in his life: that it sustains his life.

Most often, though, Bengt is capable of avoiding boredom merely by engaging in the activities he has found suitable, activities that passes the time without causing bodily dys-appearances. On such occasions, he succeeds in habituating the time in such a way that it does not emerge as something actively thematised.

Habituating time and familiarising space

As I have already pointed out above, haemodialysis patients' habituation of the time they spend connected to the machine cannot be separated from the spatial context in which it takes place. It is evident in my empirical material that the activities which result in a habituation of time are closely linked to the process by means of which the space of the haemodialysis unit is familiarised. The intertwinement of time and space does not always have detrimental effects. It may just as well produce a sense of homelikeness for the person inhabiting it. Remember Dmitry's characterisation of the haemodialysis unit as a fitness centre, bathhouse, and home, for instance, and the relationship between the flexible temporality and the patients' mobility at the self-care unit from earlier in this chapter. In what follows I will analyse this mutual habituation of time and space with particular attention to the uneventful middle part of the treatment. I do so by repeating another quote from earlier in this chapter, where Tomas replies to my question about how he is affected by spending so much time in a medical environment.

> No… affects, hopefully I get healthier when I have dialysis [laughs]. No but, affects, I mean, it's routines. You come here, you get connected, the coffee and sandwiches arrive, [you] watch TV and stuff like that, and they come and measure your blood pressure […], and then it's the additional check. Things move. It works, but it's the same thing all the time.

This account clearly illustrates the way in which the activities that pass the time also serve to make the spatiality of the unit manageable. Since there are routines that make 'things move', as Tomas puts it, the standardised medical environment that he is forced to spend time in has less of an effect on him. Or expressed differently, as the events that take place and the things that he does have become familiar, so too has the spatiality in which they occur. At the end of the quote, though, Tomas signals that the repetitiveness of the events risks making his stay at the unit dull and boring.

As Ehn and Löfgren (2010) have pointed out, in addition to facilitating one's extension into the world, the repetitions that make actions routine may themselves become boring. Routines, they contend, may 'be either a supportive corset of security, helping one along during the day, or a cultural straitjacket, trapping one in monotonous activities and blocking personal growth' (Ehn and Löfgren 2010, 80). It is this tension that Tomas's words above draw our attention towards. The activities he engages in during the treatment are not there primarily to produce personal meaning but to fit the requirement of being demanding enough to pass the time but not so demanding that they provoke the emergence of his sick body. They enable him to endure the hours he spends at the unit, but they do not provide a corporeal basis from which he may realise himself in the ways he desires.

What I want to emphasise in this section, however, is the spatiality of habits. Habitual actions are always carried out in a spatial context, a spatiality which, in turn, shapes and is shaped by these actions (Ahmed 2006, 133). To illustrate this it is enough just to attend to what is on the tables next to the patients' beds. During one treatment session at Unit 2 in Stockholm, David has on his table a newspaper, a letter from the hospital, an inflatable neck cushion, a book, and an empty plastic wrapping previously containing cotton wads. On Kerstin's table is her hearing aid, a remote control for the TV, an inhaler, cough drops, a sick bag, and the letter I gave her informing her about my project. On Göran's table are his glasses, wallet, and mobile phone, also a green comb, a purple ball intended for traction exercises, a pen, and a pillbox. Arguably, it is possible to trace what David, Kerstin, and Göran do during the treatment by attending to these things (cf. Ahmed 2006, 55). One can guess that David reads newspapers and books, Kerstin watches TV, and Göran uses the pen to solve crossword puzzles and the purple ball to exercise his hands.

What the things on the tables also reveal is that things are needed if things are going to be done during the treatment. Passing the time by being active requires things to do things with. And when such things are brought into the unit, they alter its spatiality. The haemodialysis unit, then, is no longer only a standardised space designed for medical purposes, but a place where the personal habits of the patients make an imprint. This is even more evident at the unit in Riga, where there are no tables for the patients to put their things on during the treatment. They therefore have to come up with creative solutions for where to store them. During my fieldwork at the unit I saw some tie their bags to a handle at the base of the bed, while others emptied their bags onto their beds.

To return now to Bengt, who provides a very illustrative description of how the things he does during the treatment affect the space he is in and his embodied inhabitance of it. At one point, I ask him to compare the self-care unit, which he has recently left, with Unit 1, to which he has recently moved, a request he responds to as follows:

> There's no big difference. Essentially it's exactly the same thing, because I did the same things over there [at the self-care unit]. I sat there and solved my goddamn Sudoku, and read newspapers, and watched TV. There's no difference. So, in that way, I wouldn't say that it's a problem…

The things Bengt occupies himself with during the treatment seem to erase the difference between the two units. Since he did the same things at the self-care unit that he does at Unit 1, his experience of inhabiting their respective spatialities is similar. What he does, and the things he does this with, fundamentally shape the spatiality he inhabits (cf. Ahmed 2006, 12). What happens, Bengt tells me, is that the activities he engages in during the uneventful part of the treatment allow him to turn inwards, to create a private zone by means of which he may seal himself off from his surroundings. His actions do not reorient the space of the entire unit. Rather, they allow him to shape the orientation of, and his own orientation within, the space closest to his body. By demanding his attention just enough, solving Sudoku, reading newspapers, or watching TV diverts his attention away not only from the time itself but also from the space as it is shaped by the standardised movements and positions of caregivers, patients, and objects.

When Bengt told me about this, I realised that I had observed such enactments of a private zone during all my observations at the haemodialysis units – especially at the conventional ones. I remembered that back at the beginning of my fieldwork in Riga I had been surprised to notice that the patients ordinarily did not react when the machine they were hooked up to signalled that something was wrong. Instead, they continued what they were doing while a nurse went to the machine and pushed the buttons required to turn the alarm off. When I subsequently conducted observations at the units in Stockholm, I saw the same thing. During the uneventful middle part of the treatment, the patients tended not to look up from their crossword puzzles or newspapers when the nurses approached their machine to turn off an alarm or make some other configurations. It was as if two separate realms were created, one belonging to the patient and one belonging to the nurse. The boundary between them followed the contours of the bed and the table next to it, and inside the boundary was the domain of the patient (cf. Jönsson 1998). Before I interviewed Bengt I did not understand that this might be a way in which patients manage their presence at the unit during the uneventful hours of the treatment.

This suggests that the frames and boundaries that Young deems essential for medical examinations are at work here as well. As we saw at the beginning of this chapter, according to Young (1997), during a medical examination, frames and boundaries that serve to seal the body-as-object off from the body-as-subject are constructed, thereby ensuring that the examination does not violate the patient's bodily integrity. However, such boundaries were ordinarily not necessary during the eventful procedures that initiate and terminate a haemodialysis session. The occasional emergence of the medical body-as-object into the patient's and nurse's conversations was not threatening but merely constituted a habitual interruption of their otherwise personal exchange.

So why are these frames and boundaries required here, during the uneventful part of the treatment? In a way, this question has already been answered. As we saw above, the thematisation of time and the boredom that the uneventfulness of the treatment sometimes causes risk opening up great existential depths, depths into which persons with kidney failure tend not to want to wander. In creating a private zone for themselves, what patients want to seal themselves off from is not primarily the particular medical body-as-object enacted during the treatment, but their embodiment of a life-threatening and chronic disease in general, a body-as-object that is particularly difficult to keep absent during the long, uneventful part of the treatment. In doing so, the objects – the things they occupy themselves with – play an important role. Through the newspapers, books, TV sets, headphones with music or radio they engage with, they enact a narrowly delimited, but more inhabitable and less disorienting world, a world into which they may, to some degree, extend as persons, not least thanks to their engagement with personally selected activities.

Whenever they want or deem it necessary, however, the nurses or any other medical professional may interrupt the enactment of this private realm by requiring the patient to pay attention to, for instance, the progression of the treatment or the state of his or her body. Also, the patient's body may make itself known, preventing him or her from proceeding with the activities that maintain the shielding off of the rest of the unit. The personhood enacted through personal habits, and even more importantly, the evasion of disorientation accomplished by means of these habits, is fundamentally fragile.

As we have seen throughout this chapter, when persons with kidney failure undergo haemodialysis, they are always simultaneously person and patient. For a final illustration of this, we can look once again at the things that were on the table beside David's bed during the treatment. On his table were a newspaper, a letter from the hospital, an inflatable neck cushion, a book, and an empty plastic wrapping that had contained cotton wads. If one looks closely at these things, one realises that they express a fundamental ambivalence, the impact of which becomes striking when one understands it through Ahmed's assertion that the nearness of certain objects, our orientation towards them, and the things they allow us to do shape us as embodied beings (2006, 54). Insofar as the things on David's table shape him as an embodied being, he is undoubtedly, in the most material of senses, both person and patient. The book and the newspaper extend him as a person, while the letter from the hospital and the empty plastic wrapping extend him as a patient.

Summary of the chapter

In this chapter I have conducted a thorough analysis of the practice of haemodialysis. In doing so, my focus has been primarily on the enactment of patienthood taking place here. I began the chapter by attempting to accomplish a historically informed definition of patienthood, one based on anthropologist Katharine Young's assertion that a person becomes a patient when, in a medical context, his or her body-as-object is given primacy over his or her body-as-subject. I then went on to show how haemodialysis patients, by means of repetition, come to habitually incorporate their own body as a medical object as it is enacted in the treatment practice. Through repeatedly undergoing the treatment, haemodialysis patients become familiar not only with their medical body-as-object, but also with the spatiality of the treatment unit and the objects and others that reside there. At the three conventional units – units where the treatment is led by nurses and patients undergo it for four hours, three times a week – this was primarily evident during the eventful procedures that initiated and terminated the treatment. Here, the attention of nurses and patients tended to be oriented towards each other as persons, while the medical body-as-object that was simultaneously enacted was habitually relegated to the background of their attention. Even though the medical body-as-object sometimes emerged into the foreground, due to patients' and nurses' familiarity with it, it did not pose a threat to the embodied personhood of the patient. This led me to conclude, as in the previous chapter, that bodily objectification does not always dehumanise persons or impede their extension into the world. But it may, depending on the context. And in the context of conventional haemodialysis, bodily objectifications tended to be experienced as problematic when the ill body-as-object and medical body-as-object did not align, when the habitualness was broken. In such instances, due to the inherent asymmetry characterising the relationship between patients and caregivers, the medical explanation, or the medical body-as-object if you will, prevailed over the experiential knowledge and explanation advanced by the patients. However, as my analysis revealed, the two models of explanation that were opposed here were both based on a synthesis between the ill body-as-subject, the ill body-as-object, and the medical body-as-object. In having learned to prereflectively understand their own embodiment through the technologies that enact the body as a medical object, the patients had created for themselves what I termed a 'sick body'.

This process was even more evident in the practice of self-care haemodialysis. Unlike their fellow patients in conventional haemodialysis, the self-carers were able not only to gain a deep knowledge about the treatment technologies but also to actively work on and adapt these to their unique embodiment. As they did so, the corporeal schema on which their embodied being-in-the-world was based did not remain unaffected. Rather, in their efforts to work out the ideal way of performing the treatment, the self-care patients actively created a synthesis between the ill body-as-object, the ill body-as-subject, and the medical body-as-object – that is, a sick body. At the self-care unit, the enactment of a sick body and the extensive mobility and flexible temporality required for doing so shaped not only the spatiality of the unit but also the orientations of those inhabiting it. Thus, the self-carers, to a larger extent than their fellow patients under conventional care, inhabited the treatment unit as persons. They also, to some degree, took on the role of professionals, not least through their skilful engagement with the haemodialysis technologies. Further, it was this skilful engagement with the treatment that allowed the self-carers to describe themselves as aligned with pervasive neoliberal norms such as activity, independence, and control.

Lastly, I explored the uneventful middle part of the treatment. During the hours that separate the eventful initiation and termination of a haemodialysis session nothing in particular happens, and this uneventfulness tends to be difficult for the patients to handle. The risk, the participants pointed out, is that one begins to think about the time itself, thereby not only slowing its passage, but also opening up an existential depth down which one does not want to wander. However, by patiently trying out and engaging in various activities during these uneventful hours, the patients were able to avoid orienting their attention towards time itself. Through these activities, they were also able to enact a private zone, by means of which their presence within the treatment spatiality became easier to manage. The boundaries of this private zone were not impermeable, however, since the personhood enacted within it could at any time be subject to interruption by the nurses or the patients' own erratic bodies.

To sum things up, I want finally to argue that time works two ways in haemodialysis. On the one hand, the temporality of the treatment is difficult to handle and might, if it claims patients' attention during the uneventful part of the treatment, cause disorientation. On the other hand, this temporality is to a large extent what enables patients to find ways of managing to undergo haemodialysis. As this chapter has shown, by repeating the treatment procedure time and time again, patients become capable of habitually incorporating it, and with it the medical body-as-object, which enables them to orient their attention in other directions – towards the nurses with whom they gradually become familiar, for example. It is primarily by means of this repetition, rather than some holistic approach applied by the medical professionals, that patients, particularly the self-carers, come to embody the much-cherished ideal of the patient-as-expert. This tells us that the ideals currently attached to the figure of the 'new' patient – participation, activity, autonomy, responsibility, control – must always be contextualised so that the complex situational, material, and relational circumstances of a particular medical practice are taken into account. As the next chapter will illustrate, however, in a neoliberal context that values particular forms of activity and future-orientedness, spending so much time connected to a machine is not easy.

6. The patient in the person – living with haemodialysis

In this chapter I leave the immediate context of the haemodialysis practice and move on to an exploration of the participants' life outside the treatment unit. I am interested in how kidney failure and haemodialysis enter into the daily lives of the participants. But I also direct my attention towards the work they do to make this life liveable, to find a sense of homelikeness despite the presence of the illness and treatment. In so doing, I continue my exploration of the complex relationship between personhood and patienthood, conduct a thorough analysis of the bodily, temporal, and spatial dimensions of living with kidney failure and haemodialysis, and attempt to show the ways in which this relationship and these dimensions are socioculturally embedded and normatively charged. I begin by giving a detailed account of how two of the participants describe their life with the illness and the treatment.

Veronica and Yevgeniy

At the time of our conversation in October 2010 Veronica is fifty-five years old and undergoes haemodialysis four times a week at Unit 1 in Stockholm. On Mondays, Wednesdays, and Fridays she undergoes the treatment for three and a half hours, and on Saturdays for three hours. It was after meeting a woman who managed her haemodialysis at home and underwent the treatment almost every day that Veronica decided to follow the doctors' recommendation to increase the number of treatments per week from three to four. And 'it worked,' she says. 'Now I don't want to be away, only if I have to because of something. I don't want to be away.' Veronica can choose whether or not she wants to have the treatment on a Saturday, but as she asserts so emphatically, she rarely chooses not to come. Undergoing the treatment four times a week has markedly increased her well-being, and during our conversation she often contrasts the way she feels now to how she felt before.

Like the majority of those who undergo conventional haemodialysis, Veronica describes her everyday life with the treatment as divided in two, as consisting of days with haemodialysis and days without it. On the days with haemodialysis Veronica usually does not do anything. She has learned that the fatigue and lack of energy that she experiences after the treatment take the enjoyment out of the activities she wants to engage in. She always tries to go for a walk, but not infrequently she is too tired, and eats and takes a rest instead. On the days without haemodialysis she feels much better. But the activities she engages in are still to a large extent oriented towards her body. On Tuesdays and Wednesdays she tries to exercise. She either goes to the gym – where she takes a class called 'Chi Balance', which is a less challenging class focused on body awareness and agility – or she goes for a bike ride. Up until the week before our interview she has also done water aerobics at the hospital. Exercising is something Veronica prioritises. She has noticed that it alleviates her back pains and the itch that she occasionally suffers from. Exercising also improves her sleep. On Sundays she tries to do something fun with her family – Veronica lives with her husband and fourteen-year-old daughter.

On all days of the week except Sundays, then, Veronica is primarily oriented towards her bodily well-being. This orientation is a result of her conviction that her health is essential not only for herself but also for the well-being of her family in general and her daughter in particular. As a fourteen-year-old child, Veronica contends, her daughter needs a lot of support, and in order to provide this support she must ensure that she is as healthy as possible.

Despite all the hard work that Veronica puts into her own well-being, she is unable to completely prevent her illness from emerging and her body from dys-appearing in her life away from the haemodialysis unit. She has noticed, for instance, that the treatment is affecting her memory and thinking capacity. She keeps forgetting things and feels generally obtuse, which irritates her a great deal, and in frustration she sometimes asks herself why something that has its root in her body affects her mind. What makes this even more problematic is that people around her tend to expect her to be lucid. Knowing that her disease is in her kidneys, they do not expect her to be forgetful and obtuse, expectations that sometimes make her interaction with others problematic, she tells me.

Another way in which her body dys-appears in her daily life is through her diet. Since the haemodialysis machine filters out essential proteins from her body, Veronica, like all haemodialysis patients, has been prescribed a protein-rich diet with a high concentration of meat products. The problem, she tells me, is that after a while one grows tired of meat. At the time of the interview, she is trying to remedy this problem by adding more fish to her diet.

There are other ways as well in which the effects of haemodialysis on her body extend into her life. She is, for instance, no longer capable of heaving lifting, so she does not go grocery shopping by herself anymore, but always brings her husband. The same goes for doing the laundry. The heat and the humidity combined with the heavy lifting make it next to impossible for her to be in the laundry-room, and her husband has more or less taken over this chore completely.

During our conversation Veronica repeatedly returns to the many things she has learned since she fell ill. She has learned, for instance, that she has a hard time 'carrying a lot of fluid'. 'I see other patients who can carry a lot more fluid and […] it seems like they can cope a lot better. I can't stand a lot, I get easily nauseous, very easily nauseous,' she says. This was one of the reasons behind the doctors' recommendation to increase the number of treatments per week. But although she followed this recommendation, she still has to monitor her intake of fluid meticulously. A recommendation that she has not followed, however, is to buy a blood pressure measurer to use at home. She says, 'Sometimes I can be at home and feel a little bit worried and think, "Well, now I'm going to go and buy it." But as soon as I feel better [I think], "No, I don't want it."' Veronica wants to keep her home as free as possible from things signalling disease, she tells me, 'because when I'm at home and feeling well I don't think so much about this [the treatment and the disease]'. Thus, on the one hand, when she does not feel well, a blood pressure monitor might help her understand why, while on the other, having one at home risks reminding her too much about her disease, bringing forth her body as a medical and diseased object and diverting her attention from the activities she wants to be engaged in.

But it is not only the emergence of her body as a medical or ill body-as-object that can be problematic; the time haemodialysis consumes is also difficult to manage. Veronica sometimes feels stressed because the treatment takes so much time away from everything else. Adding to this feeling is her constant awareness of the impossibility of taking time off from it. Sometimes she thinks, 'If only I could have one whole week, just one week off.' But she knows that this is impossible, a fact that affects not only her personal, but also her social life. Veronica has found a friend in one of her fellow patients at Unit 1, but since both of them are too tired to meet after the treatment, they have realised that the only time both of them are free and in a state to socialise is on Thursdays. Their get-togethers have therefore been few, but they talk on the phone regularly.

Another instance during our conversation when time emerges as something problematic is when we discuss the future. Veronica does not think about the future much, she says, and when she does, her body and its fragility and unpredictability are inevitably present. 'Mostly I think, "I hope I feel as good as I do now, or better." But that's just like a wish,' she says. In her present situation it is impossible to make plans for the future. She can only wish for her health to improve rather than deteriorate, and for what she assumes will be a premature death to take place as far off in the future as possible, she tells me. Veronica does not, as she used to, think 'Oh, maybe I'll live for ages,' but she hopes she has many years left.

The other story that I want to recount at considerable length is Yevgeniy's. At the time of the interview, Yevgeniy is fifty-six years old and is undergoing conventional haemodialysis at the unit in Riga. Like the absolute majority of haemodialysis patients in the world, he undergoes the treatment three times a week, four hours at a time. Every Tuesday, Thursday, and Saturday he gets up at half past five and goes by public transport to the treatment unit, where he arrives at half past eight. How he feels after a haemodialysis session differs. Most often his reaction to the treatment is not immediate but happens when he is on his way home. Sometimes his blood pressure rises or drops drastically, which not only makes the journey home difficult but also gives him an indication of what he will be able to do later that day. If such drastic changes in blood pressure occur, he knows that he will need to rest when he gets home. If they do not, Yevgeniy and his wife usually go into to the city for some shopping. But they never go far, since Yevgeniy runs out of energy after about three hours. 'At that time the exhaustion emerges,' he tells me.

Unlike Veronica, however, Yevgeniy finds the days between the treatments even more difficult. On these days, he tells me, he has a hard time limiting his intake of fluid. Not infrequently he drinks too much and starts to swell, which is not a pleasant feeling. Even more difficult is the two-day break between Saturday and Tuesday. It does not make things easier that this break takes place during the weekend, since this is when people usually relax their control over what they eat and drink.

To some degree, Yevgeniy tells me, the experiences he has had since he fell ill have changed him as a person. He has at least been forced to change his way of living. Now, he says, 'Everything is completely subordinated to the disease, to dialysis.' Unlike a healthy person, he has to constantly take his own well-being into account. For those who are healthy, most problems are solvable, he says. His problem is chronically unsolvable. What characterises his present way of living, he tells me, is that he cannot go anywhere, that he has to take medications constantly, and that all the actions he wishes to undertake have to be planned with regard to the illness. If, for instance, he eats something inappropriate it will immediately become evident in the subsequent lab tests. Therefore, he concludes, 'Everything is perceived through the prism of it [the illness].'

What gives him the strength to keep on struggling despite these major changes in his life is his family, he tells me. Yevgeniy lives with his wife, with whom he has two grown children. Like Veronica, he has reached the conclusion that the only way to care for his loved ones is to care for himself. He has therefore decided that for the sake of his wife, children, and grandchildren, he will fight to the bitter end in order to be as healthy as possible. 'I don't want to make them feel sad,' he says. 'That's why I'll take all the medication and do all the other things.' But this ambition is unfortunately greatly obstructed by the difficult economic situation that

Yevgeniy and his family are in. He is somewhat better off than many of his fellow patients since the pension he receives from the police force – Yevgeniy worked as a policeman before retiring – is slightly higher than the ordinary sickness compensation many of his fellow patients live on. Even so, every time he goes to pick up new medicine, he says, it feels as though he is taking money away from his family. 'It can be repeated endlessly,' he continues. 'When you have problems providing for your family, then providing for your family can be become more important than your own health.' In Yevgeniy's life there is thus, at least potentially, a conflict between his ambition to take care of his own health for the sake of his family and his wish to provide for them economically.

Finally, just like Veronica, Yevgeniy does not think about the future. He hopes to receive yet another transplant – he has been transplanted on two occasions already – but he cannot plan for it, he says, since his condition could change in an instant and suddenly make him ineligible for the procedure. At the time of our second conversation, he is having problems with his blood not coagulating properly. Until this problem is solved, he will not be admitted to the waiting list. 'I'm living under these conditions now,' he says, and then asks rhetorically, 'If I have to come here every second day, what can I plan?'

The sick body in a situation and as a personal project

In distinguishing between three different forms of dys-appearance – by looking at whether or not they are reflective and to what extent they threaten or disrupt a person's intentions – Zeiler (2010) gives the example of a man suffering from chronic pain in his leg. The man has lived with the pain in his leg for such a long time that he knows that some days are better and other days are worse. It is morning, and the man is now sitting at the breakfast table thinking about what to do that day. This question is, in Zeiler's words, 'the thematic object of his attention' (2010, 336). But in order to decide what to do, the man has to bring his 'bodily feel' from the level of prereflective awareness to the level of reflective awareness (Zeiler 2010, 336). He has to actively attend to his body in pain in order to assess what he will be capable of doing during the day. But this does not mean that he focuses on his body and the part of it that hurts in isolation. Rather, what he attends to is his 'body in a situation', a concept Zeiler borrows from Simone de Beauvoir. With this concept Zeiler wants to illustrate that, as a chronic and therefore experienced sufferer, the man is capable of attending to his body in pain '*in relation to*' his own and his family's intentions. In doing so, he does not take 'two intentional objects'; rather, his painful body emerges for him as inextricable from the context of his own and his family's situation and intentions (Zeiler 2010, 336).

This is akin to how Veronica and Yevgeniy attend to their bodies in the accounts above. By focusing on the reactions of his body after the treatment – during the bus ride back home – Yevgeniy is capable of deciding what to do during the remainder of the day. Veronica similarly attends carefully to the reactions of her body to the treatment. Her aim is to go for a walk after each treatment session, but she often does not have energy enough to do so. Evidently, Yevgeniy's and Veronica's attention to their bodies is inseparable from their intentions, from their way of orienting themselves in the world. What they attend to is a body in a particular situation, a body that is not just ill and in need of medical treatment, but that inhabits a world through intertwining itself in certain ways with particular spaces, objects, and others. They thereby become able to attend to their body in such a way that it 'does not block, but colours, [their] way of engaging with others and the world', as Zeiler puts it (2010, 336). This enables them to orient themselves towards their body in a way that redirects their intentions so that they do not experience dys-appearances that completely disrupt their intentions.

But as Yevgeniy's and Veronica's stories also show, persons who become dependent on conventional haemodialysis for their survival have to redirect their intentions quite drastically. Their ill body might not completely block their engagement with others and the world, but it does repaint it in quite dramatically different colours. Since they fell ill, both of them have learned, for example, that in order to attend to the well-being of their family, they have to attend to their own health, a realisation that has forced them to reorient their intentions towards their own body. Veronica, for example, takes her body as the primary object of attention during six of the week's seven days. Considering Leder's (1990a) contention that our inhabitance of the world relies on our being oriented from rather than towards our bodies, attending to one's body to the extent that Veronica and Yevgeniy do must logically drastically impede their wordily inhabitance. However, if one brings the concept of the body in a situation into the equation, one realises that their orientation towards their bodies also constitutes an orientation outwards, towards the world, albeit a world quite dramatically transformed by their redirected intentions (cf. Zeiler 2010, 336).

Undoubtedly, Veronica's and Yevgeniy's ability to attend to their body in a situation is the result of a learning process. At the outset, when they first fell ill, they were not capable of attending to their body in this way. Or expressed differently, since they fell ill, they have managed to create the embodied conditions necessary for orienting themselves towards their body in a situation. They have created a sick body, in the sense that I gave this term in the previous chapter. A striking example of this is the way Yevgeniy uses the notion of blood pressure to explain his experiences after the treatment and how these experiences prompt him to direct his intentions in particular ways. When his blood pressure rises or drops drastically on his way home from the treatment Yevgeniy does not experience his body only as an ill body-as-object, but also as a particular medical body-as-object. When he feels his body emerge in this way, he immediately experiences it as a change in his blood pressure. But not only that, he also immediately links this synthesis of ill and medical body-as-object to his intentions, to his situation and orientation in the world, to his body-as-subject. Without actually knowing his blood pressure, he experiences his body and the activities he will or will not engage in through this concept. By incorporating a synthesis of his ill body-as-object, his medical body-as-object, and his body-as-subject, Yevgeniy transforms his corporeal schema so that when his sick body emerges on his way home he takes all three constituents of it as one intentional object. The sick body, then, is always a body in a situation. And in continuously enacting such a sick body, persons with kidney failure transform their corporeal schema in ways that reorient them and, by extension, transform their world (cf. Zeiler 2010, 336).

As we saw in the previous chapter, self-care patients' enactment of a sick body was intimately linked to the treatment. For them, the treatment technology and practice were open to manipulation and therefore constituted aspects of their work of transforming their corporeal schemas. For conventional haemodialysis patients, this was not possible. Together with the nurses, they could alter minor details in the treatment, but they could not make any fundamental changes to it. This did not mean, however, that their medical body-as-object as it was enacted during the treatment was a fixed object impossible to alter.

As Veronica's and Yevgeniy's stories illustrate, when one undergoes haemodialysis, one's medical body-as-object does not stay within the confines of the treatment institution. It inevitably follows one home. From the initiation of haemodialysis onwards, persons with kidney failure have to live with the presence in their daily life of their medical body-as-object, a body that emerges in the form of, for example, blood pressure, bodily hydration, the level and balance in the body of various chemical substances, and so on. Consequently, just as the person enters the patient in the practice of haemodialysis, the patient enters the person in his or her life away from the treatment unit.

Like all conventional haemodialysis patients, Veronica and Yevgeniy have to limit their intake of fluid. They have to integrate the medical concept of overhydration into the mundane activity of drinking water, tea, or any other beverage. The same goes for food. Since their kidneys are no longer capable of filtering out excessive amounts of, for instance, potassium from their blood, haemodialysis patients have to reduce their intake of potassium-rich foods such as avocado, fruit juice, banana, and milk. Too high a level of this substance in the blood can upset the rhythm of the heart, causing a potentially life-threatening condition. Likewise, an excessive intake of dairy products may offset the balance of calcium and phosphate, which in the long run may cause decalcification of the bones. Thus, as Kierans argues, kidney failure 'intensifies the most banal human routines' (2005, 348). In transforming the sufferers' bodies, the disease and treatment interfere with the routines the sufferers have habitually incorporated, and the other way around.

As such, the medical body-as-object enacted in the practice of haemodialysis is by no means neutral. It does not just provide patients with neutral information about the level of particular substances in their body, but tells them what to do, what they *should* do. It is thus inextricable not only from a set of actions that need to be performed, but also from the thematisation and transformation of actions that were previously performed prereflectively. To some extent, therefore, even persons who undergo conventional haemodialysis become forced to work on their body as a personal project (Shilling 2003). The biomedical conceptualisation of and interventions in their bodily dysfunction orient them, at least when they are away from the medical setting, to autonomously and responsibly direct themselves towards their body and redirect their intentions so as to create personal strategies for managing their everyday life (cf. Rose 2007; Mattingly, Grøn and Meinert 2011).

These are important findings since previous research on chronic illness has tended to view the hospital and the home as two distinct and separate – sometimes even opposing – realms (see e.g. Strauss et al. 1984; Toombs 1992; Charmaz 2000). Strauss et al., for instance, describe the emphasis of their book *Chronic Illness and the Quality of Life* as being 'on the social and psychological aspects (not the medical) of *living with chronic illness*' (1984, viii, emphasis in the original), thereby presupposing that the medical can be separated from the social and psychological in chronically ill people's lives. As we have seen, the case is most likely the opposite; the longer a person lives with a chronic condition, the more synthesised the medical, personal, and social tend to become. Rather than being an object essentially different from the body-as-subject and the ill body-as-object, the medical body-as-object eventually becomes an aspect of the embodiment by means of which chronically ill persons inhabit the world. In concluding his account of how kidney failure has changed his life, Yevgeniy provides us with a beautiful metaphor for this process. He says, 'All is perceived through the prism of it.' And perhaps a prism is the most accurate metaphor for the 'semi-transparent' (Malmqvist and Zeiler 2010, 141) character of the sick body that persons with kidney failure live from and towards.

Camilla

As the previous section illustrated, it is in their life away from the haemodialysis unit, rather than in direct relation to the materiality and practice of the treatment, that conventional haemodialysis patients may begin to create a sick body. Persons conducting self-care haemodialysis may do both. In the sections that follow I will make a comparative analysis of the ways in which the sick body figures into the everyday life of persons undergoing conventional haemodialysis, on the one hand, and persons undergoing the self-care version of the treatment, on the other. But I will begin by giving a detailed account, as I did with Veronica and Yevgeniy above, of Camilla's description of her everyday life with self-care haemodialysis at home.

When I meet Camilla in May 2011 she has been conducting self-care haemodialysis at home for three years. After living with a functioning transplant for six years, she experienced an acute rejection in 2006, which resulted in her having to return to dialysis. Because she was young at the time, only twenty-five years old, and did not suffer from any comorbidity, she was referred to the self-care unit, where she stayed for two years before deciding to bring the machine home to her apartment. Here she takes the treatment for two and a half hours every day. After lunch she connects herself to the haemodialysis machine placed in the corner of her living room, behind her sofa. Compared to Veronica and Yevgeniy, then, Camilla not only undergoes haemodialysis more often but also for a longer total time each week – seventeen and a half hours instead of fifteen and half and twelve.

Increasing the frequency and duration of the treatment in this way has improved Camilla's health drastically, she tells me. Compared to the period preceding her transplant, when she underwent conventional haemodialysis and was constantly overhydrated, experienced drastic blood pressure drops, and had to go home and sleep after every treatment session, she is now able to do things afterwards. But more than avoiding bodily dys-appearances in the form of overhydration, blood pressure drops, and fatigue, she is now also able, quite extensively, to loosen her control over her diet and her intake of fluid. Since she fell ill she has always found it difficult to limit her intake of fluid, she says, which was a problem when she was undergoing conventional haemodialysis but is not anymore, at least not to the same extent. Because she takes the treatment so often, there is never a lot of fluid to remove from her body. The same goes for her diet. Other than making sure that she consumes a lot of protein, she does not have to think so much about what she eats. Moreover, unlike Yevgeniy, who told me that as soon as he eats something inappropriate it will show on his monthly lab results, Camilla tells me that she is able to sense when, for instance, the level of potassium is high in her body. 'I don't need a paper [test results] to know that it's high, you know. [...] That's something you learn when you manage it [the treatment] by yourself,' she says.

By conducting self-care, Camilla also improves her psychological well-being. 'The more you're capable of doing, the better you feel, of course,' she tells me. 'That's what's so comfortable and nice with home haemodialysis. You manage taking care of yourself, which adds, I believe, to your psychological well-being.' Thus, her very proficiency with the machine gives rise to a feeling of being able to care for herself, and this, in turn, contributes to her psychological health.

Like Veronica and Yevgeniy, Camilla is also actively at work with her body when she is away from the haemodialysis machine. This is how she describes an ordinary day:

> I get up [laughs a little]. I have a dog, you know, so I'm out a lot with him. Then I usually go to the gym or do something. Of course, I take care of my exercise before dialysis. I want that done before. Then I go home, cook, do what needs to be done, and take my dialysis. Then I either go to my boyfriend's place or he comes here and we do something. And I also study one night a week.

The work Camilla does on her body in the form of exercise constitutes a large portion of the life she lives away from the haemodialysis machine. Just like Veronica, she feels that exercising significantly improves her well-being. But unlike Veronica, she is interested in making physical activity her profession. When, or if, she is transplanted again, she would like to work with health and sports in some way, she tells me. The physical activity she engages in while on haemodialysis is thus part of a future-oriented vocational plan.

Despite the improvement in her health that self-care haemodialysis and physical activity have brought about, her dependence on the treatment affects her life to a fairly great degree. It is both time-consuming and draining. At present, she says, 'I feel that as a person I'm on 70 per cent of myself. That's what I can give when I'm on dialysis.' This lack of energy primarily affects her social life. When she has tried to widen her circles of social interaction beyond the persons closest to her, her body has emerged as tired and exhausted, so she has limited her interaction with others to her immediate family and closest friends. She hopes that if and when she is transplanted, this will change.

Camilla's dependence on haemodialysis further affects her life through the way it deprives her of forward movement. When she is on dialysis, she tells me, her whole life is on hold and characterised by uncertainty (cf. Kierans 2005). At the time of our conversation, Camilla has been on the waiting list for transplantation for five years, despite the fact that she was initially told she would only have to wait about a year. This uncertainty combined with her lack of energy and the time that the treatment takes prevent her from getting on with her life, from launching 'into any major project, you know, including studies', as she expresses it. For Camilla, as for Veronica and Yevgeniy, the future is very much an uncertain ground. She thinks about it, and has plans for it, but it will not start until she receives a transplant. At present, she says, she has to 'live day by day'.

Undergoing conventional or home-based self-care haemodialysis – what is the difference?

The daily life that emerges in Camilla's story is in many ways radically different from that lived by Veronica and Yevgeniy. Unlike them, she does not experience her life as divided in two, into days with and days without haemodialysis. Nor does she have to watch for and adjust to any immediate bodily reactions after the treatment. No longer experiencing severe overhydration, drastic blood pressure drops, or treatment-associated fatigue, she is now able to do things after the treatment. Further, unlike Veronica and Yevgeniy, Camilla does not have to pay much attention to what she eats and how much she drinks. She makes sure that she ingests enough protein; otherwise she does not monitor her food and fluid intake much. Camilla herself attributes these improvements compared to her time on conventional haemodialysis mainly to her ability, as a self-carer, to increase the frequency and total weekly duration with which she undergoes the treatment. Thus, while Veronica and Yevgeniy spend a lot of their time away from the haemodialysis unit oriented towards their body, Camilla is able, when she is not connected to the machine, to orient herself away from, rather than towards, her body.

If we take a step back for a moment from the level of detail we are at now, we will notice that Veronica's, Yevgeniy's, and Camilla's everyday lives have many similarities. All three are frequently and for long stretches of time engaged in actions oriented towards their body. But while Veronica's and Yevgeniy's attention to their body extends far beyond the treatment, Camilla instead extends the time she spends at the machine so that she may disregard her body when she is disconnected from it. What sets Camilla apart from Veronica and Yevgeniy, therefore, is not primarily the time she spends oriented towards her body, but the context – the when and where – of this orientation.

The work all three of them do on their bodies and the way they reorient their intentions presuppose their embodiment of a sick body in a situation – which they live as a form of personal project. In performing the treatment by herself, as the previous chapter revealed, Camilla creates a sick body. This body is in no way disconnected from her life away from the haemodialysis machine. Rather, the two are intimately entwined. It is the improved health she has experienced since she increased the frequency and total hours per week of the treatment that has motivated her to stay with this regime. The sick body she has created through aligning her body-as-subject, her ill body-as-object, and her medical body-as-object in the context of the treatment has oriented her intentions towards spending more time connected to the machine every week. She does this because it allows her to orient her intentions in desirable ways when she is away from it. For Veronica and Yevgeniy there is also no distinct boundary between the context of the treatment and the context of their life away from it, but the work they do to create and orient themselves from a sick body takes place mainly during the time they are disconnected from the haemodialysis machine.

These are not the only aspects of their everyday lives that Veronica, Yevgeniy, and Camilla share. They all experience the future as radically uncertain. Their painful awareness of the erraticism of their bodies and the uncertainty of transplantation prevents them from 'colonising the future', in Giddens's (1991) sense of the term. Akin to persons suffering from other chronic ailments, they are to a large extent forced to live in the present (see e.g. Strauss et al. 1984; Charmaz 1991; Kierans 2005). I will discuss this more thoroughly later in this chapter. I wish now to focus on the pursuit of health, which is another uniting aspect of Veronica's, Yevgeniy's, and Camilla's stories. They all want to be as healthy as possible, and much of the work they do on their bodies and selves is aimed at this end. While Camilla seems to be significantly successful in this endeavour, Veronica and Yevgeniy appear to be almost constantly enmeshed in the endeavour itself.

Health in the life of persons undergoing haemodialysis

That Camilla is not alone in experiencing improved health after initiating self-care haemodialysis is evident in the following quote by Carlos. When Carlos, after realising that he would not receive his sister's kidney, accepted that 'only dialysis remains', he wanted to try self-care. He had heard from another patient that it improved health and would allow him to live a better life. He says:

> So I talked to the doctors. I said that 'So and so and so, that's how I want it.' And now I'm getting that. And then I said to them, 'It's about me,' you know, 'I know that I need so and so many hours of dialysis to feel good, so I want those hours, and so and so many times a week, and that's my goal, in order to feel good. This is good for me and this is not good for me'. And… then I became less ill. It's like if someone becomes disabled

> and has to choose a wheelchair. He would want to have soft pillows to sit on, of course, not rocks. It's the same for me, in order to feel better; I want the best dialysis [laughs]…

Like Camilla, Carlos clearly finds that self-care haemodialysis improves his health. It makes him 'less ill', he says, and like Camilla, he attributes this improvement to the increased frequency and total weekly duration with which he undergoes the treatment. He is more 'well-dialysed' now, as he puts it later in the interview, which means that he does not 'have to go home after the treatment feeling bad'. At the time of our conversation, Carlos takes his treatment at the self-care unit, but he hopes to find a larger apartment so he can begin taking it at home. This would allow him to undergo it at night, 'for seven, eight hours, […] and that's the best dialysis you can get, because then it's like it actually should be', he says. In Carlos's view, taking haemodialysis at home during the night would imitate the functioning of healthy kidneys and would improve his health accordingly. Also, like Camilla, Carlos links the improved health he experiences with his ability to manage the treatment by himself and adapt it to his own unique embodiment.

Such links between improved health and increased control and mastery over the treatment were evident also among several of the health care professionals that I interviewed, especially those working with or guiding patients towards self-care. This is how the kidney failure coordinator Kerstin describes it:

> When you don't have control over your life then you're in the hands of others, and then feelings of anxiety and worry and things like that emerge. But when you're in control and have knowledge and feel that 'I understand', that you have a sense of coherence, that you understand why things happen, then you become calmer and feel healthier.

Similarly, Anita, an assistant nurse working at the self-care unit, told me that patients who manage haemodialysis by themselves not only become more knowledgeable about their disease but also feel healthier. In contrast to conventional haemodialysis, in which the structure of the treatment allows patients to pretend that the disease does not concern them, self-care forces patients to confront it and accept it, and this, Anita seemed to contend, is essential for their relative feeling of health. This was echoed by Ingela, who is one of the two nurses who run the home haemodialysis unit, when she linked the superior well-being experienced by self-care patients to the control they exercise over the treatment. Since control has this positive effect, Ingela asserted, her goal is that everyone who falls ill with kidney failure should be convinced to conduct self-care from the very outset of their dialysis careers. This way, they would not experience the feeling of dependence that they otherwise do.

These accounts attest to the fundamental moral and normative charge of the concept of health. This is not a new insight. As several scholars have pointed out, health has long been used as a measure of a person's or a community's alignment with pervasive moral values and cultural norms (see e.g. Qvarsell 1989; Conrad 1994; Sachs 2004). In early twentieth-century Sweden, for example, a host of educational material was disseminated among the Swedish public with the aim of teaching citizens how to live a healthy life. A healthy person was described as a person displaying 'a strong will and a strong character' and living an orderly life characterised by cleanliness and bodily control (Fioretos 2009, 129–130, my translation).

This linkage between health and morality has not decreased in significance since then. There is much to indicate that the opposite is true (Alftberg and Hansson 2012). When, in contemporary neoliberal culture, the dual process of autonomisation and responsibilisation joins forces with the demand that we live our bodies as personal projects, our ability to align ourselves with pervasive ideals such as activity, control, and independence become directly observable in the extent to which we succeed in preserving and enhancing our health (Rose 1999; Shilling 2003). But the reverse is also true; the concept of health itself becomes inextricable from these ideals. Therefore, one must display activity, control, and independence in order to be seen as healthy (Rose 2007; Alftberg and Lundin 2012). From this it becomes understandable why, as Uddenberg and Philipson (1989) suggest, health is increasingly considered an end in itself, rather than a means whereby one may realise other goals and desires.

In taking these moral and normative dimensions of health into account, I do not leave Svenaeus's characterisation of it, though I do to some extent go beyond it. As we have seen in previous chapters, Svenaeus defines health not as the absence of disease but as a process of embodied attunement that tacitly supports our understanding of the world and ourselves in it. According to this understanding, health is a 'balancing mood' intrinsic to our ability to find a place and feel at home in the world (Svenaeus 1999, 159). As such, health is always both in the body and in the world. In including the moral and normative dimensions, then, I do not alter Svenaeus's definition but simply highlight its worldliness to a greater degree.

Self-care haemodialysis does not make Camilla and Carlos feel completely healthy. They experience improved health compared to conventional haemodialysis patients, but at the same time constantly live with their body as sick. As a result, the improvement of life and health that they experience does not align them fully with the lines orienting their surroundings. Rather, they follow thinner, less persistent lines that run parallel to the most trodden ones (cf. Göransson 2012, 26). On self-care haemodialysis they may find a sense of homelikeness in the world, but compared to the healthy people around them, they are not only much more aware of the work that goes into doing so but also occasionally do not find a sense of homelikeness at all.

This is even more the case for the persons undergoing conventional haemodialysis. As Indra expresses it, 'You have to think all the time [about your health]. You can't eat what you want, you can't drink, and I also have my diabetes. So it takes a lot of thinking.' For conventional haemodialysis patients, the work that goes into feeling as healthy as possible constantly needs to be thematised. It makes the most mundane routines emerge as problematic and forces them to be constantly prepared to redirect their intentions. In doing so, however, they do not thematise their body as a pure object, but as a sick body deeply immersed in the particular situation they are in.

Bodily processes on three levels

One might get the impression in the discussion on health above that persons performing self-care haemodialysis experience a radically improved state of health compared to persons undergoing the conventional version of the treatment. However, bringing time into the equation and discussing the varying impact on the lives of persons with kidney failure of bodily process on three different temporal levels will bring more nuance to this difference. As Merleau-Ponty points out, as embodied beings, rather than being '*in* space, or *in* time', we 'belong to them, [...] [our] body combines with them and includes them' (2002, 161–162, emphasis in the original). For persons undergoing haemodialysis this often becomes painfully clear, especially for those who undergo the conventional version of the treatment. After a while, conventional haemodialysis patients notice how their body begins to follow the temporal rhythm of the treatment and how their embodied everyday life becomes divided in two, into days with and days without haemodialysis. Bodily processes that follow this temporal pattern belong to what I call 'first-level bodily processes' in the following discussion. Bodily processes located on this temporal level tend to span hours and recur on a day-to-day basis, not infrequently according to the rhythm of the treatment.

'Second-level bodily processes' span weeks or months and sometimes recur once, twice, or three times a year. Processes located on this level are often tied to another temporal rhythm belonging to the practice of haemodialysis, namely that of the monthly lab tests. Once a month persons undergoing haemodialysis, both in Stockholm and in Riga, receive the results of blood tests showing the level of various substances in their blood. These results indicate, for example, how effective the treatment has been, whether the dosage of some medication should be changed, or whether the patient in question has been eating too much or too little of something. The results of these tests may consequently cause the patient's body to emerge in a particular way, signalling the need to do certain forms of bodily work until the next month when new tests are taken. But second-level bodily processes may also be fairly detached from the rhythm of the treatment and may therefore be experienced as more or less erratic. Sometimes they recur, and eventually become more predictable and easier to handle for the sick person, even though they are erratic from the point of view of medicine.

What I term 'third-level bodily processes', finally, denote bodily transformations that are more or less irreversible and that continuously intensify, at least as long as the person with kidney failure undergoes haemodialysis. These bodily processes are generally the result of the person's long-term embodiment of the disease and dependence on the treatment. This does not mean that they are constantly present in the sense of always being thematised. Rather, they emerge occasionally, either as a sick body in a situation, forcing the sick person to redirect his or her intentions, or as a bodily dys-appearance that disrupts his or her intentions completely.

Contrary to what the description above might suggest, there are no sharp lines between the bodily processes on the three temporal levels. One bodily process may very well be located on two temporal levels simultaneously or might slip from one to another. For example, a recurring bodily process on the second temporal level may move to the third level if the person experiencing it realises that this is something he or she will be forced to live with. With this qualification in mind, in what follows I will make use of these three levels of bodily processes to address differences and similarities between the daily lives of persons conducting self-care haemodialysis and persons undergoing the conventional version of the treatment.

First-level bodily processes

As Veronica's and Yevgeniy's stories illustrated, persons who undergo conventional haemodialysis tend to experience their body as following the rhythm of the treatment, as being a certain way on days with haemodialysis and another way on days without. While they often experience nausea and headaches due to overhydration before a treatment session, they tend to witness the emergence of their body in the form of intense fatigue or drastic changes in blood pressure after it. On the days without haemodialysis they often feel better, but they still orient themselves towards their body. They monitor what they eat and drink and tend to their health by exercising, for example. Bodily processes on the first temporal level thus have a significant presence in the lives of persons undergoing conventional haemodialysis. I wish to illustrate this below with a few more examples from my empirical material.

Pyotr, who undergoes the treatment at the unit in Riga, experiences the division between the days with and the days without haemodialysis in a quite radical way. He says:

> On the days with dialysis, I'll say it again, I have headaches and [feel] weak and tired after the treatment. I lie down and sleep for about three hours. I wake up in the evening, have dinner, watch a movie, and go [to sleep] again. So, roughly speaking, that day is lost. […] But during the other days I feel nothing. Then I'm an absolutely normal person. I work that day. I have a job. Days with dialysis differ strongly from days without dialysis.

The difference between the days with and the days without haemodialysis in Pyotr's life is striking. It is as if he is ill every other day and well every other day. Pyotr seems to be quite defenceless in relation to the reactions of his body to the treatment. Regardless of how much fluid he has to remove from his body during a haemodialysis session, he always has to go home and rest afterwards. He therefore considers these days to be lost. Perhaps this is so because he is new to haemodialysis. Having undergone it for only four months, he has yet to create and live from a sick body in a situation. But one can also see the way he handles this double nature of his everyday life – resting on the days with the treatment and working on the days without – as a strategy in itself. In the absence of any efficient way of working on his body to avoid the fatigue and headaches following the treatment, he reorients his intentions.

This is essentially also what the more experienced haemodialysis patient Filips does, with the one exception that, since he has been enacting a sick body in a situation for a while, he has realised that his fatigue is directly linked to the amount of fluid that is removed during the treatment. He may therefore affect the way he feels after the treatment by ingesting less fluid. Filips says:

> If I drop 3.5 kilos, then I feel good. But if I drop 5, then I have to lie down for two to three hours. I go home by car, and then I lie down. First I have lunch. Sometimes I have it here at the unit, sometimes at home. Then I take a nap for two to three hours. Then I'm able to do something, do some work around the house or go shopping with my family.

Unlike Pyotr, Filips is able to affect the way he feels after the treatment by regulating his intake of fluid. But this is not an easy task; it is hard not to drink when one is thirsty. On some occasions, therefore, Filips has to remove as much as 5 kilos of water from his body, and he knows this will affect his well-being detrimentally. One the positive side, however, Filips does not, like Yevgeniy, have to await his reaction to the treatment in order to reorient his intentions. It is enough for him just to pay attention to how much fluid needs to be removed. But the principle is the same. Filips and Yevgeniy both orient themselves towards their sick body in a situation and reorient their intentions so that they will not experience dys-appearances that disrupt their intentions.

To sum things up, one can contend that persons undergoing conventional haemodialysis continually experience bodily processes on the first temporal level. But they are not completely defenceless in relation to these processes. Once they have been undergoing the treatment for a while, they develop strategies that enable them to avoid bodily dys-appearances that disrupt their intentions, either by working on their bodies or by reorienting their intentions, or both.

Persons undergoing self-care haemodialysis, on the other hand, are generally able to entirely remove, rather than avoid, bodily processes on the first temporal level. In increasing their weekly treatment dose by taking the treatment more often, they do not experience the fatigue, the drastic changes in blood pressure, the nausea, and the headaches that persons undergoing the conventional version of the treatment do. Nor do they have to pay so much attention to what they eat and how much they drink. As Hans tells me, there is simply not enough time between his treatments for him to ingest an amount of fluid that would cause problems for him. 'That's the thing,' he asserts. 'I mean, if I'd been having the treatment three times a week then it would have been a crisis. Then I would probably have had to remove six, seven litres every time.' But now, when he takes the treatment five to six times a week, the removal of fluid from his body is a 'caress', as he puts, a gentleness in the treatment that allows him, like Camilla, to be active afterwards.

Far from experiencing themselves as completely healthy, though, persons conducting self-care haemodialysis – just like those undergoing the conventional version of the treatment – are relentlessly aware of themselves as suffering from a chronic illness. It is not just their dependence on and the time consumed by haemodialysis that gives rise to this awareness, but the emergence of their body as ill on many occasions and in many ways in their daily lives. Marianne, for instance, feels that she is ‘more tired than others’, that is, than people in general. ‘That’s difficult to measure, of course,’ she says, ‘but I’m tired a lot.’ Added to this fatigue is the severe loss of muscle mass that she has experienced since she underwent haemodialysis for the first time twenty-three years ago. She has recently started attending a gym class in an effort to rebuild her body, but she is not able to do much, she says, because she quickly runs out of energy. The illness and treatment have also significantly affected her endurance. In a frustrated tone of voice she tells me that because of her lack of endurance, she finds it difficult to engage in one of her favourite activities, going to the woods to pick mushrooms. After a while in the woods, her legs and back give out and she has to go back to the car and wait while her husband continues. ‘There are limitations all the time,’ she concludes.

But are the bodily emergences that Marianne describes examples of first-level bodily processes? In what follows, I will argue that they are not, and locate them on another of the three temporal levels.

Second-level bodily processes

Bodily processes on the second level are, as I mentioned above, to some extent tied to a rhythm upheld by the treatment, namely that of the monthly lab tests. Once a month, all haemodialysis patients are presented with their own body as a medical object in the form of the levels of various substances in their blood, but these results are not at all confined to the realm of medicine. They extend far into the daily lives of the sick persons, telling them, for instance, whether they have been eating right. Thus, the test results constitute an aspect of the force, inherent in contemporary biomedicine, that compels sick persons to create a sick body. In their encounter with the monthly lab tests, persons undergoing haemodialysis are faced with the task of linking the levels of various substances in their body to the actions they undertake in their everyday life. As a consequence, many seem to experience the test results as a kind of key revealing how they have lived during the previous month.

Contrary to the impression that the above may give, not all of the participants experience this as something negative. Rune, for example, greatly values the information that the monthly lab tests give him. He says:

> Well, I want to be informed about… well, about how I feel, you know, about what I don't feel but what the tests reveal. […] I always ask for a copy of all the test results so that I can compare with the previous ones. 'Okay, that has changed, oh!' And then maybe you ask about that and you receive an explanation and, if possible, information about what you can do about it…

Comparing the latest test results with the ones from previous months allows Rune to discover tendencies of improvement and exacerbation. 'I am in no way an expert,' he says, 'but I want to know about what concerns me, and what I can do to improve it.'

Since he has cultivated and still continually cultivates an acceptance of the medical explanation of his suffering, Rune understands that the deviation from normal of a substance in his body may impair his health in the long run, even though he does not experience any such impairments at the moment of receiving the test results. He also understands that what he does when he is away from the treatment unit may affect the result of the tests, and is therefore interested in knowing if and what actions he may undertake in his life away from the unit to improve them. But he also, largely of his own accord, expands the time frame of the monthly lab tests by comparing them with each other. This allows him to follow variations in test results over long stretches of time and relate them to how he has acted on his body in his life away from the haemodialysis unit. In doing this, Rune creates a sick body for himself, a sick body which enacts a line that is possible for him to follow, a line which he hopes not only makes him as healthy as possible in the present but also generates a return in the form of improved health in the long run (cf. Ahmed 2006, 17).

Marianne, who manages her treatment by herself at home, describes her relation to the monthly lab tests in very much the same spirit as Rune. 'I'm always interested in my test results,' she says, 'always interested in what I can do and how I can change and how I can affect.' Like Rune, Marianne also actively accumulates the monthly test results into a line that she tries to follow. However, self-carers tend to act more confidently in relation to the test results than their fellow patients in conventional haemodialysis. As we saw above, Camilla claimed that she does not need to wait for her test results to know that the level of potassium in her blood is high, and assigned this ability to the knowledge she has gained as a result of her performance of the treatment. When her potassium is high, she says, ‘I get this creeping feeling. Then I know, “Okay, it’s my potassium that’s high,” and then I take a resonium.’ Camilla has clearly accomplished an embodied synthesis between a particular creeping bodily feeling and the level of a chemical substance in her body, and through remedying this by taking a pill, she gains a certain amount of control over a bodily process that would otherwise follow the temporal rhythm of the monthly lab tests. Thus, unlike Rune, Camilla is to a certain extent able to disrupt the rhythm defined by the treatment. In doing this, she is not distancing herself from her own body as a medical object. Rather, it is her incorporation of this body that allows her to act upon it.

Not all second-level bodily processes are bound up with the rhythm of the monthly lab tests. Some, for example, are caused by infections that are common among the general public – such as the flu and tonsillitis – but hit chronically ill populations harder. At the time of my interview with Hans, for instance, he was slowly recovering from a period of very low levels of haemoglobin in his blood caused by a severe streptococcus infection. The infection had been so severe that it had caused a biliary colic and forced Hans to stay at the hospital for nine days. In the process, he was also temporarily taken off the waiting list for transplantation. With such low levels of haemoglobin, the doctors informed him, he would not be eligible for the procedure if an organ were to become available for him. ‘But at least we’re working on it,’ Hans says, referring to the efforts he and his doctors have made to raise his haemoglobin level. Although it hit him hard, there are things that can be done about the bodily dys-appearance that this particular second-level bodily process caused.

For Eva it has been worse. As I have already mentioned, persons who undergo haemodialysis have to increase their intake of protein. Put bluntly, they have to eat a lot of meat. Thus, their appetite is essential for their well-being. ‘But it’s difficult sometimes,’ Eva tells me. ‘If you feel worse some weeks, then it’s very difficult. Then it shows on your test results.’ Eva occasionally experiences periods during which the relationship between her appetite and her health goes into a vicious circle. When, sporadically, her general feeling of health deteriorates, she experiences difficulties in ingesting enough protein, and this, in turn, impairs her health even more. Eva and her caregivers seem to experience these periods as quite erratic. They can neither predict them nor affect their duration. This clearly frustrates Eva, and it is evident that, since the act of eating lies outside the realm of medicine, she feels personally responsible for ensuring that such periods do not occur, and, by extension, do not re-enter the realm of medicine as bad test results. Fortunately, she tells me, her appetite at the time of our conversation ‘is functioning well’, an expression that may be interpreted as an attempt to place appetite within a medical framework, among the other biological functions of the body over which one has little control.

Second-level bodily processes may thus be both intimately linked to and temporally disconnected from the monthly lab tests that all haemodialysis patients undergo. They may also be varyingly difficult to predict and affect, and therefore varyingly disorienting. As my analysis above has shown, the bodily processes that are intimately connected to and to a large extent created by the monthly lab tests are easier to affect. The lab tests may even function as tools for preventing bodily dys-appearances causing disrupted intentions in the present and in the future. But then there are the erratic second-level bodily processes, those that seem to live a life of their own, and that are disorienting to a greater degree, not least because they dys-appear both as ill health and as bad test results, dys-appearances that are difficult, if not impossible, to prevent. Unlike first-level bodily processes, then, the differences between conventional and self-care patients are smaller, and sometimes even non-existent in the case of second-level bodily processes.

Third-level bodily processes

As I have already mentioned, the term third-level bodily processes denotes bodily transformations that are more or less irreversible and that continuously intensify, but which tend to make themselves known only occasionally. Bodily processes on this level are generally the result of a person's long-term embodiment of kidney failure and dependence on haemodialysis. It is on this level that I want to place the fatigue and lack of energy Camilla experiences when she tries to extend her interaction with others beyond the persons closest to her. It is also here that I want to place the lack of endurance and energy that Marianne experiences when she is in the forest picking mushrooms. As both of their stories reveal, even though this fatigue and lack of energy and endurance primarily emerge as reflective dys-appearances in association with certain activities, they are the result and bodily expression of long-term and constantly ongoing bodily processes located on the prereflective level of their awareness. On haemodialysis, Camilla estimates that she is at 70 per cent of herself, while Marianne feels that she is 'more tired than others'. These are bodily processes that go beyond the rhythms of first- and second-level bodily processes. They are constantly prereflectively present and, as such, constitute fundamental constituents of the body in a situation that both Camilla and Marianne embody. This has led Camilla to orient her intentions away from socialising in wider circles, thereby avoiding the dys-appearances that might otherwise occur. Marianne, on the other hand, seems to be unwilling to give up the activity of picking mushrooms, and thereby refuses to reorient her intentions in line with her sick body, consequently experiencing the dys-appearance of her body and the disruption of her intentions. This clearly frustrates Marianne. Her inability to engage fully in one of her favourite activities causes her to experience moments of an unhomelike being-in-the-world.

Like many other haemodialysis patients, Marianne tries to counteract her continuous loss of energy and muscle mass by exercising. But while this activity strengthens her body, it also provokes its dys-appearance. During the gym class she attends she often quickly runs out of energy and has to interrupt her participation. Here, Camilla, Veronica, and Rune seem to be more successful. By exercising her body Veronica has managed to alleviate the back pains and itching – symptoms common among haemodialysis patients (cf. Kierans 2005, 344) – that she previously suffered from. Rune says he 'has proof' of the effectiveness of the exercise that he engages in. Once every six months he meets with a physiotherapist who measures the strength and endurance of his body, and he has made progress, he tells me. 'I'm aware that in my situation it is even more important to exercise than it would be if I were healthy, because it goes downhill fast, especially when you come up in age,' Rune says. Working out allows him, if not to completely terminate, then at least to slow down the third-level bodily processes that his long-term embodiment of the illness and dependence on the treatment has instigated.

Thus, just like the self-carers, persons undergoing conventional haemodialysis experience and try to act on third-level bodily processes. Veronica, for instance, in addition to the lack of strength and endurance that prevents her from going grocery shopping and doing the laundry by herself, is experiencing a deterioration of her memory and thinking capacity. While she has reoriented her intentions so that she never goes to the grocery store without her husband and leaves the laundry almost entirely in his hands, finding strategies for avoiding bodily dys-appearances caused by her increased forgetfulness and obtuseness is more difficult. Since the disease she suffers from is located in the kidneys, not just the people around her but Veronica herself seem to expect her memory and thinking capacity to be intact. When it proves not to be, she sometimes finds herself in situations that she experiences as unhomelike and disorienting.

There is a particular paradox, however, that persons conducting self-care haemodialysis, to a larger extent than persons undergoing the conventional version of the treatment, experience and feel forced to try to resolve. This paradox emerges when first-level bodily processes are related to third-level processes. As we saw above, in order to eliminate first-level bodily processes, self-care patients invariably increase their weekly dose of haemodialysis. But although this prevents them from experiencing the fatigue, headaches, nausea, and overhydration that afflict conventional haemodialysis patients in direct relation to the treatment, it does not eliminate the long-term deteriorating effects. In fact, the opposite is quite likely the case. The risk is imminent that in increasing their weekly dose of haemodialysis and taking the treatment more frequently, they are exacerbating and accelerating third-level bodily processes. That this is a risk consciously experienced by self-care patients is evident in Camilla's story, for example. Camilla tells me that among the things she searches for on the Internet is information about the long-term effects of taking haemodialysis as often as she does. She wants to know how she should balance her desire to maximise her health in the present with her desire to minimise the long-term damages of the treatment on her body. She says, 'Because, since I'm so young, I want to spare my body as much as possible while I'm on dialysis. But I still want to feel as good as possible.' Clearly, these two desires are likely to stand in opposition to each other. What sets the self-carers apart from their conventional fellow patients is not their awareness of the long-term effects of the treatment on their body – persons undergoing conventional haemodialysis are also painfully aware of this. What sets them apart from each other is the ability of the self-carers to affect their haemodialysis dose and thereby, in the long run, affect how much the treatment wears on their body. It is uncertain whether Camilla found what she was looking for on the Internet, but she has concluded that taking the treatment a little every day is the least poor way in which she may reconcile the two temporal levels opposed here. This is the conclusion, it seems, that most persons who manage their own haemodialysis have reached. When they begin to perform the treatment by themselves they invariably increase the frequency and weekly duration with which they undergo it.

Perhaps this decision is to a large extent a result of their confinement to the present. Above, Veronica, Yevgeniy, and Camilla all mentioned the impossibility of bringing the future into their present actions. When the prospect of receiving a transplant is highly uncertain and one experiences one's body as exceedingly unpredictable and increasingly fragile, the future loses its link to the present and becomes a largely uncontrollable and formless mass. It is evident in previous research that such a loss of the future and confinement to the present is a common experience among persons who fall chronically ill (see e.g. Strauss et al. 1984; Charmaz 1991; Kierans 2005; Russ, Shim, and Kaufman 2005). Kierans, for instance, writes that chronic illness 'shatters our illusions of the predictable, the linear; our unquestioning faith in the idea of the next step: a tomorrow!' (2005, 342). It is the uncertainty or, to use Mol's vocabulary, erraticism characterising the ill body that accomplishes this shattering. Achieving a colonisation of the future, in Giddens's sense of the term, therefore becomes virtually impossible. Here is what Marianne has to say about this:

> Marianne – Don't talk about the future with me. That's something I hate, talking about the future. You know, people who want to speculate – 'Well, when we retire from work' – you know, things like that, I'm allergic to that. I'm almost allergic to talking about what we're going to do next summer. 'We'll see. It will solve itself once we get closer [to summer].' I've been that way all the time since I fell ill, not before.
>
> Martin – No, and it's because you never know?
>
> Marianne – No, I don't know what state I'll be in and, as a matter of fact, I don't know if I'll be alive, either. I mean, things can happen, we know that.

It is evident in Marianne's words that engaging in a colonisation of the future constitutes a pervasive norm. Although, due to the erraticism of her body, she is not able to engage in it herself, she constantly finds herself in situations where other people do, people who, perhaps unwittingly, sometimes encourage her to do so as well. This has made her allergic to it. Not only is she herself incapable of thematising the future in this way, but other people's talk about it serves to bring her bodily erraticism to the fore. In opening up another time dimension than the day-to-day orientation she tries to uphold, other people's colonisation of the future spurs the dys-appearance of her body as a body incapable of extending its intentions into the future. In such instances, it is not only the potential deterioration of her body that comes into view, but also the very end of its existence. Thus, for persons suffering from a life-threatening and chronic illness, talk about the future generates questions not just about what actions they will be able to perform in the future, but about whether they will be around at all. It brings death into life in a painful way (cf. Russ, Shim and Kaufman 2005).

Not all participants are as aggravated by other people's talk about the future as Marianne, but the great majority emphasise the impossibility of being future-oriented, of planning for the long term. In all of these accounts the erraticism and fragility of the body take centre stage. It is the unpredictability characterising their embodied inhabitance of the world that prevents them from colonising the future. If he were to try planning for the long term, Ivan tells me, he would live in 'complete chaos'. It is necessary instead to 'try to live a day at a time'. Living day-by-day can therefore be said to constitute a mode of coping, by means of which chronically ill persons 'avoid or minimize thinking about further disability and death' (Charmaz 1991, 178). As such, it is future-oriented to a certain extent. In enabling sick persons to reorient themselves in the sense that they may find means to create a fairly well-functioning daily life, living day-by-day is future-oriented insofar as it entails a production and reproduction of a particular, albeit narrow, line. Lines are always to some extent future-oriented, as Ahmed points out (2006, 21; see also Charmaz 1991, 48). What sets chronically ill persons apart from the healthy population, however, is the scope and form of their future orientation. While healthy persons may plan years ahead, aiming for self-actualisation, persons suffering from a chronic condition ordinarily only make plans for a couple of days, or a week at most.

As the division of bodily processes into three temporal levels that I have made here has shown, the differences between persons undergoing conventional haemodialysis and persons performing self-care haemodialysis are located primarily at the first temporal level. By increasing the frequency and weekly duration with which they undergo the treatment, self-carers become able to remove many of the bodily processes on the first level. But just like their fellow patients in conventional haemodialysis, they experience second- and third-level bodily processes, some of which they are able to avoid or tame by orienting themselves from their sick body in a situation and some of which they experience as dys-appearances disrupting their intentions.

These are insights that provide us with a more detailed knowledge about the outcomes of self-care, insights that attest to the complexity at work when patients become responsible for managing their own treatment, and nuance the often-heard claims that this form of care entails a straightforward path to improved health. As we saw, for example, self-carers tend to live in the middle of a paradox that is hard to resolve, in which first-level and third-level bodily processes stand in opposition. But this should not lead us to downplay the improvements in their situation that self-carers actually experience, which, as the following sections will reveal, extend beyond the immediate realm of the body.

Time in the life of persons undergoing haemodialysis

Conventional haemodialysis

If, after a while on conventional haemodialysis, it becomes possible to regain some control over one's body by living from and towards it as a sick body in a situation, managing the temporal intrusion of the treatment into one's life seems to be more difficult. Conventional haemodialysis forces itself into one's existence and demands one's conformation with its standardised regime. As we saw in chapter 3, a majority of the participants in this study claimed that this is something one simply has to accept. There is no choice, since death is not an alternative. Even so, achieving such acceptance is difficult. As Veronica's words above revealed, she feels frustrated about the time the treatment takes and the impossibility of taking time off from it. She sometimes thinks, 'If only I could have one whole week, just one week off.'

When I ask Rune to describe how undergoing haemodialysis affects his life, he says:

> Rune – Well, as you know, now I go on Mondays, Wednesdays, and Fridays, and… I have other commitments, so to speak, in addition to dialysing. But it gets very fragmented, my whole life. And everything has to revolve around the dialysis times. You can switch times, but dialysis has to be there, and therefore there are a lot of other things you can't do. And that's negative, I think.
>
> Martin – Is it primarily the time it takes [that concerns you] or is it also that you are physically affected by the treatment in your daily life?
>
> Rune – Well, of course… a completely healthy person, so to speak, doesn't have to think about how he or she feels. But I feel pretty well anyway so, I mean, I don't consider that to be the worst part. The worst thing is: I'm not in control of my own life…

This way of characterising life with haemodialysis is common among the persons undergoing conventional haemodialysis whom I have met. The treatment regime invades one's life, fragmenting it, disrupting its coherence. One can, to some extent, influence its temporal distribution, but it must always be there. Taking a week off from haemodialysis is impossible. Worse than having to pay attention to one's health is the complete submergence of one's life under the regime of the treatment. It is possible to get to know one's body and come to regain a certain amount of control over it. But the time loss is absolute. One has no choice but to leave home and spend four hours at the unit connected to the machine. Not surprisingly, therefore, many describe a feeling of being bound. When I ask Eva what she considers to be the worst thing about haemodialysis, she says:

> Well, it's being bound. That's what's worst, I suppose. And to know that you have to come here three days a week, and you leave at seven in the morning and you're not home until, well, one, maybe one, one-thirty. And sometimes you have other examinations after dialysis, and then you get home even later. Then there's not so much time at home.

A conventional haemodialysis session may only be four hours long, but when travelling time and additional examinations are added, the time consumed by the treatment is considerably longer. In Eva's case it is more than six hours. Having to dedicate so much time to haemodialysis makes Eva feel bound. Adding to this feeling is her awareness of the fact that the treatment has to be repeated three times a week. Thus, it is not only the actual time loss that makes living with conventional haemodialysis difficult, but also the never-ending repetition of the treatment. The only way out of this perpetual repetition is transplantation. I ask Filips if being on haemodialysis has changed how he looks upon himself and his life:

> Yes, of course. I think that I would have so many things [to do] if I didn't have to undergo dialysis. Even when I had a kidney [was transplanted], I had a different lifestyle and time schedule. I could do more things, make plans, for example, or something like that. But now dialysis is the most important activity, and only then come all other things. Dialysis reorganised my life.

Thus, akin to Rune and Eva, Filips experiences living with a problematic body – as he did also when he was transplanted – as less disorienting than having to hand over control of his time to a standardised treatment regime. When he was transplanted he was not only able to be more active, but he also had greater influence over the timing and nature of his activities. At the time of the interview, however, he experiences his life to be governed entirely by the regime of conventional haemodialysis.

Why do Rune, Eva, and Filips feel that being in control of their time is so important? Why does living in line with a temporally standardised and time-consuming treatment make them feel as though they have lost control of their life? An answer to these questions can be found, I believe, in Giddens's writings, in which he links the control of time to the pervasive neoliberal project of self-actualisation. He writes, 'Self-actualization implies the control of time […] because it is the essential condition of achieving satisfaction at any given moment – of living life to the full' (Giddens 1991, 77). In order to align oneself with the dominant line towards self-actualisation – in order to fill every moment with personal meaning (cf. Svendsen 2003) – one has to be in control of one's time. Here is where conventional haemodialysis patients fail. The perpetual repetition of their visits three times a week to the treatment unit as well as their embodiment of an erratic and chronically ill body revokes their control of time, making them unable to strive towards their own self-realisation. It is not strange, therefore, that Rune feels that his inability to control his time has led to a total loss of control of life.

Self-care haemodialysis

Descriptions like those offered by Rune, Eva, and Filips above are to a certain extent present also in the self-carers' stories. Hans, for instance, describes being bound as one of the main negative aspects of his dependence on haemodialysis. But he quickly adds that self-care gives him the opportunity to influence the timing and length of his treatments. He says, 'If you don't want to have three days times [multiplied by] five hours, you can divide it into six days, or into five days – five times three – then you sit for three hours. So it's possible also to turn the negative aspects around.'

What Hans seems to say here is that the possibility he has of influencing when and for how long he undergoes the treatment to a certain extent alleviates his sense of being bound. This is an experience that he shares with the majority of the self-care patients I met during my fieldwork. Even though they are as dependent on the haemodialysis machine as their fellow conventional patients, and invariably spend more hours a week connected to it, they feel less bound by it.

There are many clues to why this is so in Hans's own story. When I ask him how many times a week he takes the treatment, for example, he says, 'Well, it's between, say, four, five, six times. It depends on what I feel like. There you have the flexibility.' What he values is 'being able to decide "No, I don't want to sit these five hours. Forget it, the sun is shining, I want to go outside now!" Then you can end the treatment prematurely, and maybe sit for an hour longer next time.' Besides 'cheating with the machine' in this way, as he puts it, he also appreciates the possibility of deciding from one day to the next if he wants to take a day off from the treatment. Calling a conventional haemodialysis unit and saying, 'No, I'm not coming,' would make the staff 'pissed', he believes. 'But when you manage everything by yourself, it doesn't matter much,' he continues. It is evident that Hans greatly values this type of flexibility. In fact, when I look back at the transcripts from my interview with him and from our more informal conversations, I struggle to find any pattern at all for when and how often he undergoes haemodialysis. The only regularities I can find are that he usually takes Saturdays off and that he prefers to undergo the treatment in the morning.

Although Marianne manages haemodialysis by herself at home, she has chosen to undergo the treatment with a little more regularity than Hans. According to the routine she has developed, she takes the treatment in the evenings. This suits her well since she is often a little tired afterwards and because 'in the evenings you usually do calmer stuff', like watching TV, which she tends to do while undergoing haemodialysis. She usually takes the treatment five nights a week. But before a new week begins she always takes a look in her date book to see what activities she has planned, and if she has a lot to do, she reduces the number of treatments to four. During the week of our interview, for example, she has her son's birthday and a ballet performance to go to, and will therefore only undergo four treatment sessions. But as a rule of principle she never takes less than four treatments and never goes below fifteen hours of haemodialysis per week. Within these boundaries, however, she tries to leave room for as much flexibility as possible. When her daughter comes to visit with her boyfriend, for instance, and they end up in an exciting card game after dinner she occasionally skips the treatment all together. She also sometimes departs from her regular routine of undergoing haemodialysis in the evenings and takes the treatment in the daytime. 'You know, that's a freedom I also need to have,' she tells me.

Marianne greatly values the possibility of performing haemodialysis at home. In her view, anyone who is not too advanced in age and still has enough energy to manage haemodialysis in their home should do so. 'It's incredibly valuable to be able to take control of your own life more, which you do when you have it at home,' she says. In her story, she associates this ability to take control of her life directly with the possibility that home haemodialysis gives her of sculpting the temporality of the treatment. 'I feel very independent,' she says. Managing the treatment at home 'gives me […] a sense of freedom with the machine, I think – with my life, actually'.

To a large extent, then, it is their ability to influence the temporality of the treatment that orients persons conducting self-care to feel less bound by it. Rather than having to sculpt their life according to a pre-established and static treatment regime, self-carers are able to some degree to mould the treatment in line with a desired life. And because they are in control of their time to a greater degree than persons undergoing conventional haemodialysis, are able to engage in activities favouring their own self-actualisation. This is only true to a certain extent, of course. As the previous sections revealed, self-carers, just like conventional patients, are painfully aware of their embodiment of kidney failure, an awareness that, for example, makes them incapable of performing a colonisation of the future. Adding to this is the time they spend at the haemodialysis machine. All self-carers invariably undergo the treatment for a longer time per week than their fellow patients in conventional care, though – paradoxical as it may seem – they feel less bound by it.

This paradox is resolved if one recognises that what is at stake here is time not in a quantitative but in a qualitative sense. It is not essentially the amount of time available that matters, but the nature of this time and the ability of the sick person to determine the nature of this time. In having the opportunity to decide when and for how long they undergo haemodialysis, the time the self-carers spend away from the treatment gains a new quality, both in the sense of being characterised by increased health and in the sense of being something they control the contents of, something they may fill with activities of their own choosing. Through this quality of time, the self-carers come closer to aligning themselves with the ideal of self-actualisation, and this allows them to conceptualise their life with haemodialysis in terms of the neoliberally charged concepts of independence and freedom. It is because she can choose when and for how long she undergoes the treatment, Marianne tells me, that she is able to experience a 'sense of freedom with the machine'.

Here it is relevant to address also the theme of flexibility. Marianne's and, even more so, Hans's stories were both permeated with this theme. The quality of time, and thereby quality of life, that they experienced was to a large extent due to the possibility they had of spontaneously altering the treatment regime. If the weather was nice or if they had people over, they could decide to end the treatment early or not undergo it at all. Being able to exercise flexibility in this way was something Marianne linked to the freedom she experienced after she began managing the treatment by herself. This echoes Richard Sennett's contention that, in neoliberal culture, 'we imagine being open to change, being adaptable, as qualities of character needed for free action – the human being free because capable of change' (1998, 47).

In the context of neoliberalism, the theme of flexibility ordinarily emerges in discussions about corporations and labour markets. In order to be successful on a free market, enterprises and workers alike must exhibit flexibility (Lindqvist and Lindqvist 2008). But this process of flexibilisation, research has shown, has not remained within the confines of the corporate world and the labour market. In recent decades it has extended far beyond these settings and become a widespread ideal, to the extent that it is now seen as an aspect of a healthy body (Martin 1994; Fioretos 2009) and a form of human capital held by individuals who are capable of realising their personal goals and desires (Sennett 1998; Harvey 2005). Flexibility, then, is an essential feature of the project of self-actualisation. It is not so strange, therefore, that Hans and Marianne so adamantly emphasise the ability they have as self-carers to exercise flexibility. By underscoring that they are in control of their time in such a way that they are able to be spontaneous and open to change, they de-exceptionalise their dependence on haemodialysis and normalise the life they live with it.

Voices critical of self-care

Interestingly, temporality is a central feature of the criticism that some persons undergoing conventional haemodialysis direct at self-care. Of these critics, Rune is the one who elaborates most. This is very likely due to the pressure he has felt from the medical staff to begin managing the treatment by himself. Ever since he first encountered haemodialysis in the early 1980s, he has had to deal with the nurses' and doctors' promotion of self-care and has therefore been forced to polish his arguments against it. It was this resistance, among other things, that prompted the head nurse at Unit 2 to suggest that I interview Rune. I got the impression that his caregivers thought it strange that a relatively able-bodied and knowledgeable person like Rune did not desire the increased independence, health, and control that self-care could offer, and therefore saw him as an interesting interview subject for me. What irritates Rune is that the staff's puzzlement about his resistance to self-care has meant that they keep bringing up the subject. They have had a hard time accepting that he does not want it, he tells me. But now, after their latest discussion, a couple of weeks before our conversation, he hopes that the message has sunk in.

The major reason Rune does not want to manage the treatment by himself is the additional time it takes. He estimates the time loss incurred by the tasks he would have to perform as a self-care patient – dressing the machine, connecting himself to it, disinfecting it afterwards, and so on – to be one hour. The possibility of having this hour at his own disposal rather than devoting it to the treatment is primarily what leads Rune to turn down the offer of self-care. He says, 'I think it's [conventional haemodialysis] comfortable and good. I get more time for myself, so to speak, and that's why I've declined the offer, which seemed to come as a surprise to the person in question.' Placing so much emphasis on the loss of one hour may seem pointless, but it is consistent with the observations I made during my fieldwork at the self-care unit, where the ambition among the great majority of patients was to make the tasks associated with the treatment as time-efficient as possible. Unlike the patients at the self-care unit, however, Rune regards this time loss as sufficient for turning down the offer of self-care.

Rune also likes the way conventional haemodialysis allows him to disregard the treatment technologies. He says, '[With my history in the pulp and paper industry] one could perhaps be inclined to believe that I am very interested in the technological… But I've had way too much technology in my life [we both laugh].' He is careful to point out, however, that he is knowledgeable about the treatment; he understands the meaning of the signals the machine emits and the amounts to which its parameters should be set. But he is uninterested in deepening his engagement with it further, he contends.

Bengt similarly views the time loss that self-care incurs as the main drawback of this version of the treatment. As I mentioned in the previous chapter, when I interviewed Bengt he had just recently moved from the self-care unit to Unit 1 in Stockholm, where he was conducting a form of semi-self-care. He inserted the needles and programmed the machine by himself, but left the dressing and priming of it to the nurses.

Bengt's choice to begin managing the treatment by himself, in the first place, had not been made totally without the influence of his caregivers. It was 'their proposal', he says, and he was initially not so enthusiastic about it. At the time, he had been undergoing conventional haemodialysis at Unit 1 and 'liked it there'. One advantage of Unit 1 was that it was possible to buy a warm lunch there after the treatment. This was not possible at the self-care unit.

'But couldn't you just have turned down the offer and stayed at Unit 1?' I ask Bengt. It wasn't as simple as that, he contends. In fact, the main reason his caregivers gave for moving him out of Unit 1 was that they wanted to vacate some treatment places there. This was hard to argue against, Bengt tells me. He had to accept the transfer. But first he was moved to the conventional haemodialysis unit one floor above the self-care unit. And here they 'hassled me to move downstairs', where, he was told, 'everything was so good'. 'But I didn't think it was good at all,' he says. After some time, however, Bengt learned to appreciate some aspects of self-care haemodialysis. 'What's good about self-care', he tells me, 'is that I know where to insert the needles and I have a sense of what I'm doing with myself.' That is, it has given him an increased self-knowledge. He even states that 'when I began to insert the needles by myself, I found myself, so to speak.' And subsequently, as he gradually increased his weekly haemodialysis dose, he found 'more ways of being'.

Now, back where he started and conducting a form of semi-self-care at Unit 1, Bengt has realised that 'self-care is not a universal solution'. Like Rune, he views the main disadvantage of this form of treatment to be the time loss it involves, but by means of the semi-version he presently conducts, he can keep many of the advantages of self-care without having to engage in its most time-consuming tasks. In leaving the dressing, priming, and disinfection of the machine to the nurses while he still controls its parameters, Bengt feels he has found a version of haemodialysis that he can live with.

It is evident in both Rune's and Bengt's accounts that some persons undergoing conventional haemodialysis in Sweden experience forceful pressure to start conducting self-care. This pressure is explicitly exercised by the caregivers, who promote the procedure by attaching the promise of health, independence, and control to it. Framed like this, self-care emerges as the self-evident treatment form of choice. Therefore, if, like Rune, one turns down the offer of self-care, one will appear a little awkward. In a neoliberal context, where the ideals of independence, health, and control are so pervasive and are seen to be achieved ideally by engaging in body projects and projects of self-actualisation, self-care emerges as the best way of managing health issues. It is by engaging in activities that are conceptualised as self-care that one may increase one's well-being and begin to live more normally. The activities that do not fit into this frame are concealed and barely seen as activities at all. From this point of view, the desire to have a warm meal after treatment is dismissed as irrelevant. So too is Rune's wish to keep an extra hour of time free by remaining on conventional haemodialysis. His choice to pay attention only to the aspects of the treatment technology that he finds relevant is translated as passivity. Or in other words, the activities he does engage in – attending to some of the machine's parameters and actively making use of his extra hour – are not seen as activities at all. Since they are not part of the self-care routine, they are made invisible.

Restricted mobility and ability to travel

During my two conversations with Yevgeniy he repeatedly returned to the fact that haemodialysis prevents him from going anywhere, from travelling. 'You can only go to the seaside or to your summerhouse on a day off. That's all,' he said. Haemodialysis is thus not only a time-consuming treatment, but it also fetters its patients to a particular place. One's life as a person in need of haemodialysis hinges on one's recurrent return to the space in which the machine is placed. One has to remain fairly close to this space at all times, which restricts one's mobility considerably. This necessity gives rise to a fair amount of frustration among the participants in this study, a frustration that does not primarily concern the spatiality within which the treatment takes place, since, as we saw in the previous chapter, one eventually gets used to and finds ways of managing, and thereby reorienting, this spatiality. What frustrates the participants is the restricted mobility itself, a frustration that interestingly enough is primarily expressed as irritation at not being able to travel.

Although he is ambivalent about undergoing transplantation, Ivan says that at least it would allow him to escape the boring and fettering haemodialysis routine. 'Sometimes', he says, 'I am so tired of coming here for dialysis. Sometimes I think "I won't go." Then my mom comes, pushing me to go here.' If he were to undergo transplantation, he contends, he would not only escape dialysis, but he would also become more mobile. He says:

> I could travel. I could go abroad somewhere for a week and rest. Now I can only travel for two days, but first I need to inform [the staff at the unit]

> that I won't come on Saturday. And then on Monday and all other days [that week] I would undergo dialysis for four hours instead of three.

Going for a week-long vacation is presently impossible for Ivan. Haemodialysis prevents him from doing what many healthy – and indeed transplanted – persons do, occasionally going on a trip abroad for the sole purpose of having a rest from the strains of work and everyday life. But he may go away for two days. Since he undergoes haemodialysis four times a week, however, doing so would force him to take one day off, preferably Saturday. He would have to inform the doctors and nurses at the unit that he will not come on Saturday and increase his haemodialysis dose during the entire subsequent week, work that Ivan clearly finds demanding and restricting.

The restriction on mobility may also be stigmatising. This is evident in Lidija's story. Unlike healthy people, Lidija has to spend her entire summer in the city. She cannot, as she used to, spend several weeks in a row at her country house. Like Ivan, she can only go away for a maximum of two days. She says, 'Now you go on Saturday, and on Sunday evening everyone stays in the countryside, but you have to go back [to be in time] for dialysis on Monday.' Lidija's dependence on haemodialysis and the way it restricts her mobility sets her apart from her neighbours at her country house. While everyone else may choose to stay – especially during the summer when they are on vacation – she has to return to the city on Sunday evening in order to undergo dialysis on Monday morning. Thus, not only is Lidija prevented from doing what she wants to do, but she is also unable to align herself with the line followed by the majority, which may be stigmatising and disorienting.

The persons who undergo haemodialysis in Stockholm tell a similar story. Here, however, there is much more elaborate support for patients who wish to travel and, while away, undergo the treatment as a guest at a haemodialysis unit in the destination country. This support is provided both by the patients' association, which arranges group tours, and by the nurses and doctors, who actively encourage patients to travel and help them arrange guest dialysis sessions. During my fieldwork in Riga, the possibility of travelling and undergoing the treatment somewhere else was seldom mentioned, and very few patients seemed to have any experience of this. Ilona, who was actively engaged in the Latvian patients' association, told me that she tries to encourage the members to travel, but to little avail. The two main explanations for her lack of success in this matter, in her view, are the relative absence of information and encouragement from the medical professionals combined with the lack of financial resources among the patients – most of them simply cannot afford to travel.[61]

The fact that more elaborate support exists in Sweden does not mean that all Swedish patients travel. In fact, only a few of the participants spoke of having had 'guest dialysis' at units during travels. Rune was one of them. When he underwent haemodialysis for the first time in 1981 he was still working as a consultant, an occupation that involved a lot of travel. He initially managed to continue working full time, but the treatment forced him to cut down on his travelling. Even so, during the periods before and between his two transplantations, Rune went to England, Norway, Germany, Austria, and several cities in Sweden, where he underwent 'guest dialysis' sessions. When his second transplant ceased to function in 2002 and he was told that he was not eligible for a third, he retired from work. But he has continued to travel. Since 2002, Rune and his wife have visited places far and near, such as India, Norway, Ireland, and Mallorca. Travelling contributes to his feeling of living an active life, he tells me. His only concern when undergoing dialysis at foreign units is the level of hygiene. The unit in Mallorca, for instance, was privately run, which, Rune tells me, meant that they were not as concerned with hygiene as he would have preferred. 'It's all business,' he says.

Being able to travel despite his dependence on haemodialysis has clearly allowed Rune to retain a grain of his former active and mobile lifestyle. The thought of undergoing the treatment abroad is not so easily digested by everyone, however. One should keep in mind that Rune was already a very experienced traveller when he fell ill. His work had taken him to places all over the world. Although it would undoubtedly have been a bigger loss for Rune than for many of his fellow patients had he been forced to end his travelling, he also had an advantage over them in that

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[61] I address the economic situation of the participants later in this chapter.

travel was and had long been an integral part of his life. This is particularly evident when one compares Rune's story to Tomas's. When I ask Tomas how the treatment has affected his everyday life, he says:

> Tomas – I can't travel anywhere. If I want to go somewhere, I have to do it on Saturdays and Sundays, because I mean, a week in the Canaries… Sure, guest dialysis is a possibility, but it's too much trouble.
>
> Martin – Is it too much trouble?
>
> Tomas – Yes.
>
> Martin – Yes.
>
> Tomas – But as I said, I'd like to go to the Canaries, because I've been there many times.

The beginning of this quote echoes the words of Ivan and Lidija. As a person in need of haemodialysis, one's mobility is restricted; one can neither travel far nor be away for a long time. This is difficult to handle since it gives rise to feelings of being bound and sets you apart from the people around you. But Tomas seems to find this restricted mobility frustrating for yet another reason. When he says that he wants to go to the Canaries because he has been there so many times, he signals that what he has lost is not only his mobility but also a sense of continuity. His dependence on haemodialysis prevents him from continuing the habit of visiting the Canaries regularly, from reproducing the line that promised a return in the form of travel and mobility. That Tomas experiences this as a disorienting loss is evident since it is the first thing he mentions when I ask him how his everyday life has been affected by his dependence on haemodialysis.

Despite the painfulness of this loss, however, Tomas is unwilling to engage in the work that would make a trip to the Canaries possible. He offers two explanations for this. The first concerns the time it takes to plan the trip. The planning has to be initiated a year in advance, he tells me, which he thinks is way too long. He does not elaborate much on why this is so, but it is reasonable to believe that it has to do with the erraticism of his body and the resulting impossibility of making plans for the future. Like his fellow patients, Tomas is aware of the unpredictability of his body and has therefore begun to narrow the scope of his future-orientedness. Planning for a trip a year in advance is almost impossible from this perspective. Despite meticulous preparations, he has no way of knowing in advance if he would be in a state to travel on the day of departure.

The second explanation Tomas offers concerns his deficient language skills. On his previous trips to the Canaries, when he was not dependent on any medical assistance, he could get by well without being fluent in English or Spanish. Now he is afraid that he would not be able to communicate his personal preferences to the nurses and doctors responsible for his care. Thus, when the trip is no longer solely recreational but also involves a medical treatment without which Tomas would not survive, he believes he would have to have more knowledge of the languages spoken there, that the little English and Spanish he speaks would no longer suffice. Hence, even though it is perfectly possible to travel while on haemodialysis, there are obstacles that must be overcome, and for some, the effort required to do so outweighs the pleasure of the trip. But as Tomas's story indicates, this does not make the resulting feeling of being bound any less frustrating and disorienting.

Even for a person who is used to managing haemodialysis by herself at home, overcoming the obstacles associated with travelling with haemodialysis may be difficult. This is evident in Marianne's story. She says:

> We've [Marianne and her husband] done a few things. We went to Rome for an extended weekend, Thursday to Sunday. My husband and I made a joint effort to plan the haemodialysis session that I would undergo. We booked it through the Internet. It was possible; it is possible! It is. But, as I said, it requires some courage. You can't be scared. You have to feel that 'I dare to do this'.

In light of this, the question arises why the desire to travel, to be mobile, is so strong that it motivates some to go through all the trouble involved in making the arrangements necessary for travelling with haemodialysis, and throws others – those who are unwilling or unable to overcome these obstacles – into a disorientating feeling of being bound. Several scholars have emphasised the centrality of mobility in neoliberal culture (see e.g. Sennett 1998; Fioretos 2009). Foucault, for example, argues that mobility forms an integral constituent of the human capital making up the enterprising and free individual so cherished within neoliberalism (Foucault 2008, 230). In today's globalised consumer society, Zygmunt Bauman contends, 'One difference between those "high up" and those "low down" is that the first may leave the second behind – but not vice versa' (1998, 86). Bauman calls the ones high up 'tourists'. Tourists are mobile. They cross national and continental borders, for work and for pleasure. 'Vagabonds', conversely, are left behind. They never move of their own choosing. They are moved by outer circumstances or simply forced to stay put. Bauman does not have haemodialysis patients in mind, of course, when he writes about vagabonds, but rather migrants and impoverished people living in Third World countries or in the poor areas of Western cities (1998, 92–102). But it is not so far-fetched to conceive of persons undergoing haemodialysis as vagabonds, as people who 'want to be allowed to be tourists – like the rest of us' (Bauman 1998, 94). It is, I believe, partly this desire that shines through in the participants' frustration over not being able to travel. This is not only a desire to be mobile. It is also a desire to be normal.

The ambiguous home

Falling ill with kidney failure and becoming dependent on haemodialysis not only restricts mobility; it also alters one's relationship to one's home. This was evident already at the beginning of this chapter where we saw how the sick body in a situation embodied by the participants reoriented their intentions in their home environment. By means of a synthesis of the body-as-subject, the ill body-as-object, and the diseased body-as-object, the participants developed ways of preventing dys-appearances that entirely disrupted their intentions. Filips, for instance, knew that if more than 3.5 kilos of fluid was removed from his body during the treatment, he would be forced to postpone the 'work around the house' that he had planned to engage in. He knew that he would first have to rest, and only then could he make himself useful at home. As it is for the majority of persons undergoing conventional haemodialysis, then, Filips's home primarily constitutes a place for rest during his days with haemodialysis.

But since he fell ill, Filips has also begun to experience his home as a risky place. At the time of our conversation, he is living in a house together with his mom and his siblings. As with any private house, Filips's home is in constant need of maintenance, work that he tries to do on his time away from the treatment. But ever since he fell ill he has experienced an impaired sense of balance, which makes the maintenance work more difficult. Once, he even fell and hurt himself quite badly. This experience has made him more aware of his bodily limitations and has motivated his family stop him from engaging in certain tasks. Thus, the bodily changes that Filips has experienced since he fell ill have forced him to orient himself differently in his home, a reorientation that has made both his body and his home emerge as potentially problematic.

As we saw at the beginning of this chapter, since she fell ill, Veronica has experienced the loss of one of her home's rooms. Due to her illness she is no longer able to carry heavy things and is sensitive to damp and warm environments. This has made the laundry-room an uninhabitable space for her. In a sense, therefore, her home has grown smaller since she fell ill. What is also evident in Veronica's story is that she simultaneously experiences her home as a safe haven and a risky environment. On the one hand, it is a place where she may orient her attention away from the disease and treatment: 'When I'm at home and feeling well I don't think so much about this,' she tells me. But this safe and disease-free character of the home is constantly under threat, a threat that is posed not only by her own diseased body, but also by recommendations coming from the doctors. Veronica has been advised, for example, to buy a blood pressure measurer for her home. But at the time of our conversation she has yet to follow this recommendation, and this is because she wants her home to be as free as possible from things signalling disease. But when she occasionally worries about her condition, she sometimes feels the need for the recommended device. On such occasions she feels that its presence in her home would not be problematic. Thus, it is apparent that, for Veronica, the meaning of her home and the things in it changes according to the way she bodily inhabits it.

But the biggest threat to the safe and disease-free character of her home, it seems, is posed by the temporality with which she inhabits it. Since Veronica no longer works, she goes directly home after the treatment. And when she arrives, no one is there. Her husband is still at work and her daughter is at school. 'Those days are quite lonely,' she says. She therefore greatly values the small talk she usually engages in with her fellow patients before she leaves the unit after a treatment session, '[because] I come home and, I think, they also come home and spend their time alone,' she says. On the days without haemodialysis, Veronica ordinarily feels better and is able to leave her home and engage in various activities. But on treatment days, her inability to be active, coupled with the absence of her family, makes her home an existentially risky place to inhabit.

This inability to be active is one of the main reasons behind Veronica's unwillingness to manage haemodialysis at home. As a home-haemodialysis patient, one runs the risk of becoming isolated and spatially fettered to the home, she contends. 'When you meet other people, you get distracted, and you often need that,' she says, and continues, 'It's easier to fall into these more serious thoughts when you're at home, I think, than when you're away from home.' Managing the treatment by herself at home would thus deprive Veronica of one of her coping strategies – thought monitoring. While conventional haemodialysis forces her away from her home, allows her to interact a little with others, and enacts a spatiality with which she may associate disease and treatment, home-haemodialysis risks turning her home into a place where, due to the absence of other people and the presence of medical technologies, she can no longer orient herself away from her embodiment of the disease and her dependence on the treatment.

In what follows, I will continue to use home-haemodialysis as an example of how the home is implicated, and perhaps increasingly so, in the care of chronically ill persons. By means of this example, the integral role of the home as a place where persons with kidney failure may retain a degree of homelikeness and the potential threat to this homelikeness posed by medical technologies and practices become evident. First, I will make a brief theoretical departure into the concept of the home in general and in relation to contemporary health care in particular.

What is a home?

The meanings of the concept of home are multiple and culturally and historically contingent. It is therefore necessary to determine what version of the concept of home we are concerned with here. We can begin by stating that when the participants and I use the word 'home' during our conversations, we primarily intend a built environment inside which one or several persons live.

Narrowed down in this sense, and viewed from a phenomenological perspective, a home is a place that is deeply intertwined with its inhabitants' embodied selves. Not only is it a place where the inhabitants spend a lot of their time and engage in activities of an intimate and private nature, but it is also a place that they arrange and furnish themselves, whether with a particular interior design idea in mind or quite unreflectively as a result of their routines and habits. From a phenomenological point of view, a home can be understood as a place where body and space have become intimately aligned, an alignment which has come about both as a result of the enactment of prereflective habits and routines and as a result of the reflective arrangement of things in space (Young 2005; Alftberg 2012; Göransson 2012). In the words of Iris Marion Young, a home is 'an extension of and mirror for the living body in its everyday activity' (2005, 140), a relationship which, as Filips's and Veronica's stories revealed, can become problematic when a person falls ill.

By means of the reflective and prereflective bodily movements that orient the things and the spatiality of a home, its material totality becomes invested with the bodily presence and history of its inhabitants. But the opposite is also true; the orientation of the home's objects and spatiality extends and orients the embodied selves that inhabit them. A home is therefore, in a deeper sense than most other spaces, formative of the identities of the embodied persons who live there. This does not mean that we can once and for all settle our identities through the materiality of our home. Even though it has the important function of preserving and affording continuity to our embodied orientations, the act of preservation is itself a 'creative and moral task' that consists in reconstructing 'the connection of the past to the present in light of new events, relationships, and political understandings' (Young 2005, 144) – or a changed body, as in the case of kidney failure.

The home, as much as the orientations of the people who live there, can be viewed as processual openings onto the world (Alftberg 2012, 110). As such, it is never sealed off from its cultural and historical context. Indeed, thanks to its formative powers it frequently becomes the main site for the construction and repetition of pervasive normative orientations. This double nature of the home – being both preserving and variable – makes it inherently ambiguous (Young 2005, 123). Women in particular have long experienced this ambiguous nature of the home, Young contends. While, on the one hand, they have been able to found their identities on the positive values associated with it, on the other hand, they have been fettered to it and have experienced themselves as captives of its space and values (2005, 129). Similarly, Göransson shows how non-heterosexually oriented persons not infrequently find it difficult to extend into and orient themselves within the primarily heterosexual spatialities of contemporary Western homes. But due to its malleability and profound intertwinement with its inhabitants' routines, Göransson illustrates, non-heterosexually oriented persons also eventually find ways of making their homes their own (2012, 133–148). In view of this, one can contend that a home is at once a highly normative and rigid place and a private, intimate, and processual place open to its inhabitants' orientational work.

To further untangle the complex concept of home and narrow it down some more, one can argue that what we are concerned with here is essentially a modern and to a large extent Western conception of the home, not least in the context of home-haemodialysis in Sweden. This is a home that, despite its inherent ambivalence, is generally associated with positive values (Young 2005, 125; Karlsson 2008, 69). It is a place, according to Rob Imrie, to which positively charged concepts such as 'privacy, security, independence and control' are attached (2004, 746; see also Alftberg 2012, 108). But it is a 'commodified home', Young argues, in that it has become the main site for the exercise and display of a person's 'consumer freedom' and 'social status' (2005, 130–133). It is thus not particularly far-fetched to contend that what we are dealing with is to a large extent a neoliberal home. By increasingly viewing the individual and his or her family as an autonomous unit responsible for actualising and enhancing their own well-being through choice, neoliberal policy has made the home one of the most important sites for such activities (cf. Rose 1999, 74; Harvey 2005, 23).

Not surprisingly, therefore, the home plays a central role also within the ideological framework orienting contemporary health care (Karlsson 2008, 68). According to Karlsson, the home is increasingly seen today as a natural place for care – as opposed to the unnaturalness of medical institutions. It is understood as a place that affects patients' recovery favourably, as a spatial setting that possesses therapeutic powers on its own. At home, it is said, patients not only feel safer and experience as higher quality of life, but they also enjoy and may cultivate increased autonomy and empowerment. The home, proponents of home-based health care contend, is a place that allows patients to regain a degree of control over their care and their life (Karlsson 2008, 208–209).

That these ideas were present in the context of home-haemodialysis was evident, for instance, in my conversation with one of the nurses responsible for teaching patients how to manage the treatment at home. The main advantage with home-based haemodialysis, the nurse, Ingela, argued, is that 'you control your own life. It's not dialysis that controls the patients' lives, but the patients who control dialysis.' This, she contended, not only increases patients' empowerment, but also enhances their well-being.

The symbolic, practical, and material dimensions of the opposition to home-haemodialysis

Despite the conviction among health care professionals of the superiority of home-based self-care and the moral and normative ideals with which this form of care is charged, many of the haemodialysis patients I interviewed during my fieldwork had turned down the offer of managing the treatment by themselves at home. The explanations they gave for this generally contained a combination of symbolic, practical, and material dimensions (cf. Hansson 2007; Åhdal 2012). Indeed, these dimensions were often intimately intertwined in their accounts.

When I asked the participants about the opportunity of managing the treatment at home, the answers I received were ordinarily of two kinds.

They were either akin to Bengt's – who said, 'I don't want the hospital at home' – or Rune's – who said that he wanted the treatment 'to be managed at the hospital'. These two modes of explanation have in common that they aim to retain a firm distinction between the home and the hospital. But the former of the two tells us something more. It tells us that, somehow, along with the treatment, follows the hospital. Along with the haemodialysis machine, the needles, filters, tubes, and the very practice of the treatment follows the spatiality of the hospital. Here the conflation of symbolic, practical, and material aspects becomes apparent. Not only do the things and actions that enter the home in home-haemodialysis symbolise the hospital, but they also practically and materially originate from and enact the hospital. Even though the hospital does not actually enter the home, things ordinarily found there do, and the combined symbolic and material powers of these serve to induce the feeling that the home has been invaded by the hospital.

What is more, in order to accommodate haemodialysis, the home itself has to be altered. A water purifier and piping have to be installed and room has to be made not only for the machine itself but also for the bulky boxes of material that are delivered once every other week. This leads some, including Rune and Bengt, to contend that they simply do not have room enough, or *a* room, to house the treatment. While Rune tells me that 'there isn't room enough' where he currently lives, Bengt is of the opinion that the practice of home-haemodialysis requires a spare room about the size of a normal bedroom, which he does not have at the moment.

There are clearly symbolic dimensions at work here. This is evident, for example, in Carlos's story. At the time of our conversation, Carlos conducts haemodialysis at the self-care unit. But unlike Rune and Bengt, he hopes soon to be able to bring the treatment home. The problem is that he does not have a spare room to house the machine, and finding a bigger apartment is proving difficult.

During our conversation, Carlos echoes Bengt's words, saying that he does not want to have the hospital at home. Yet this does not dissuade him from wishing to manage the treatment at home. If he is just able to find housing that enables him to tuck the treatment away in a spare room, he seems to say, the presence of the hospital will not make itself known as intrusively. Why this is so becomes apparent when he describes one of the main advantages of home-haemodialysis:

> That's why it's important for me to have dialysis at home, because then I don't have to go anywhere. [Instead] it's sort of like having to go to the bathroom or take a shower. I have to go to that room and connect myself [to the machine] for two and a half hours to feel well, and then when I'm done I turn it off and close the door: 'Goodbye!' Then I can do something else. But having to leave my home and take the subway and then go there [the self-care unit]… well, it becomes like a job.

This quote provides us with many important insights. Most obviously, it tells us that one of the main advantages of managing haemodialysis at home is not having to commute anywhere in order to undergo it – an advantage that I will come back to later. Carlos's words also illustrate that the home, and particularly certain configurations of it, may have a de-exceptionalising effect on the treatment. If the home is configured in such a way that there is a particular room where the haemodialysis machine and appurtenant materials may be housed, the treatment may become as un-exceptional and mundane as any other basic need ordinarily met within its walls, Carlos seems to say. In this sense, Carlos's view is largely aligned with the ideology orienting contemporary health care towards increasing its presence in the home. But what is seldom taken into account in this ideological and largely rationalistic orientation is the powerful symbolic charge of medical materials and practices. It is because of this symbolic charge that Carlos finds it necessary to place the haemodialysis machine in a spare room, since if it is not contained correctly, its symbolism risks seeping into the rest of the home, depriving it of its safe and private nature, turning it into a place that signals dependence rather than independence. The positively charged home is thus not powerful enough in itself to stave off the compelling threat of the hospital, materialised through the presence of the haemodialysis materials and the treatment practice. In order to say 'Goodbye!' to the treatment after he has undergone it, as Carlos hopes to be able to do, it has to be contained in a separate room, behind a closed and locked door. If he is able to do this, then undergoing haemodialysis at home may have a de-exceptionalising effect, becoming akin to such basic needs as going to the bathroom or taking a shower.

This echoes the words of Veronica above. The reason she does not want to buy a blood pressure measurer for her home is that she wants to keep it as free as possible from her disease. This tells us that when treatment technologies are brought into the home, not only the hospital but the disease itself enters it (cf. Åhdal 2012, 33). In signalling both hospital and disease, the presence of the treatment technologies makes the presence of a sick person who is dependent on an advanced medical therapy much more apparent, and this, in turn, makes it difficult to associate the home and its sick inhabitant with the positive values ordinarily attached to it. Imrie (2004) illustrates this eloquently in his study of how persons with physical disabilities experience their homes. Due to their disabilities and the entry of various material aids into their homes, many of the participants in Imrie's study experienced their home as being at odds with the privacy, security, independence, and control currently associated with it. Rather than a beneficial privacy, they felt a distressing confinement. Rather than independence and control, they felt that their difficulty of moving around in their home and their dependence on others enhanced their disability.

In the case of haemodialysis the risk is also that, along with the hospital- and disease-infused medical technologies, comes the patient: the risk is that the sick person becomes a patient in his or her own home. As I have already mentioned, this happens even if no treatment technologies are brought into the home. Irrespective of the form of haemodialysis, the patient enters the person who enters the home in the form of a synthesised sick body from and to which the person is oriented, and in the form of diets, fluid restrictions, and other medically informed practices aimed at the body. However, when the haemodialysis machine and the appurtenant materials enter the home and the treatment starts to be practiced there, the presence of the patient becomes all the more apparent. As a result, the home itself as well as the identities of the persons who live there run the risk of becoming even more ambiguous.

This seems to have been what Camilla worried about when she considered beginning to manage the treatment at home, a concern that, at first, made her reluctant to bring the machine home. Just like Bengt and Carlos, Camilla worried that along with the haemodialysis materials and the treatment practice would come the hospital. ‘I thought it would constantly feel like you were in a hospital environment,’ she says. But there was also another concern troubling her. She worried that the presence of the haemodialysis machine in her home would affect her relationships with friends and family, that the sight of the towering presence of the machine in her apartment would be a dramatic experience for the people who came to visit her. ‘I wanted to manage dialysis privately, not involve a lot of people in it,’ she says.

Even though the home is ordinarily associated with privacy, it is a place to which we invite people of varying proximity to us. In our homes we spend time with friends, family, colleagues, and neighbours. For such encounters the home offers a comfortable and intimate setting that often serves to deepen our relations. But it also functions as an expression of the inhabitant’s personhood (see Young 2005). By means of the spatiality of the home, the person living there tells his or her visitors who he or she is. It is in this context one should understand Camilla’s worries about the potentially detrimental consequences of home-haemodialysis on her relationships. What she worried about was the risk that the conspicuous presence of the haemodialysis machine in her home would display a side of her that she preferred to keep private. Being in her home, the machine would inevitably become linked to her, and with it its entire symbolic materiality, signalling medicine and patienthood, connoting disease, dependence, and passivity, which, she worried, would make her personhood and home ambiguous in the eyes of the people who came to visit.

So why, then, did she finally choose to begin managing haemodialysis at home? If the risks were as significant as she worried they would be, why did she not simply continue managing the treatment by herself at the self-care unit? What finally made Camilla take the step to begin conducting home-haemodialysis was her affection for the two nurses working with it. ‘I wanted them as my nurses,’ she says, ‘and they were in home-haemodialysis.’ Thus, from the outset, it was not the increased autonomy, control, and health associated with home-based haemodialysis that motivated Camilla to begin conducting it, but her affection for two of the nurses. But when she did start, she noticed that her ability to decide when and for how long she would undergo the treatment grew, and this enhanced her well-being and her sense of being in control. She also noticed that it was pleasant to be at home after the treatment. It had sometimes been onerous to get home from the self-care unit, but now she was able to engage in activities of her own choosing directly after the treatment.

She noticed further that her worries associated with the entry of the treatment technologies into her home were unfounded. Although she chose to place the machine in her living room, behind the sofa, no one has reacted much to its presence, she tells me. ‘Most of the people around me don’t care. It’s more like, “Well, okay, you do that,” which is nice.’ Nor has the presence of the treatment technologies had any significant impact on Camilla’s own sense of her home. The technologies have not turned her home into a hospital, as she worried that they would. But she is glad, she tells me, that she did not place the machine in her bedroom. Since she is currently in a relationship it would not be nice to have it there, she says. This last statement to some extent signals that, despite the mundane presence of the haemodialysis machine in her living room, it might begin to exert a detrimental symbolism if it were moved to the bedroom. Thus, even though neither Camilla nor Marianne, who also conducts home-based haemodialysis, feels that the machine’s presence has had any negative effects on themselves and their homes, Rune’s, Bengt’s, and Carlos’s worries that it might, are not entirely unfounded.

Making ends meet

Besides experiencing the transformation of the life they live inside the four walls of their home, many persons with kidney failure also witness a deterioration of their economic situation following the initiation of haemodialysis. As we saw in the beginning of this chapter, Yevgeniy experiences a conflict between his ambition to take care of his own health and his ambition to support his family economically. He feels that every penny he spends on medications is a penny less for his family. For him, this is clearly one of the greatest difficulties he faces as a person with kidney failure.

Veronica, on the other hand, whose story I also recounted at length in the beginning of this chapter, did not bring up the theme of her economic situation during our conversation herself. It was only when I asked her about it that our discussion began to revolve around this issue. Except for a protracted conflict with the Swedish Social Insurance Agency, which resulted in her receiving a permanent sick listing, thereby losing her employment, Veronica and her family have not experienced any economic difficulties, she tells me. Their economic situation has become worse since she fell ill, she says, but when her husband's salary is added to her sickness benefits, they have enough to live on.

It is interesting to compare Yevgeniy's and Veronica's situations. Both are in their mid-fifties, and neither has been able to continue working since they began undergoing haemodialysis, but both of them have quite a long working life behind them. A significant difference between their respective situations, however, is that Veronica's partner works, while Yevgeniy's does not. The contribution to their joint finances that Veronica's husband's salary makes is significant, of course, but so too is the difference between Veronica's and Yevgeniy's sickness benefits. While Yevgeniy receives 210 Latvian Lats (LVL)[62] (approximately 300 euros) per month, including LVL 50 for transportation, Veronica receives 11,000 Swedish crowns (SEK) (approximately 1,150 euros). Although it is necessary to include the cost of living in any comparison of sickness benefits between two countries, the difference between Yevgeniy's and Veronica's benefits is indicative of the differing economic conditions that Latvians as compared to Swedes are thrown into when they fall chronically ill and become unable to work. This is a difference that runs like a thread through my empirical material. When haemodialysis is initiated, the Latvian participants enter a much more precarious economic situation than the Swedish do.

In the wake of the neoliberal 'shock therapy' that Latvia underwent in the early 1990s, the economic inequalities in the country have grown significantly (see e.g. Eglitis and Lace 2009). Among the groups that have been hit particularly hard by poverty and economic marginality are pensioners and heavy industrial workers, but also persons whose working capacity has been limited due to illness. While the cost of living has increased drastically since Latvia gained independence in 1991, the benefits awarded

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[62] On January 1, 2014, the Latvian currency Lat was replaced by the Euro.

to senior citizens and sick persons have not, not infrequently falling below the 'survival minimum' defined by the state (Eglitis and Lace 2009, 332; see also McKevitt, Luse, and Wolfe 2003). The participants in this study, for instance, generally mentioned amounts between LVL 100 and LVL 150 – excluding the LVL 50 they receive for transport – when I asked them about their sickness benefits. To give some idea about the inadequacy of this support we can compare it to the survival minimum, which, in late 2007, was set at LVL 141 (Eglitis and Lace 2009, 337).

As a thirty-eight-year-old husband and father undergoing haemodialysis at the unit in Riga, and as a 'normal young man who needs to relax and have fun', the sickness benefits Dmitry receives are nowhere near sufficient. At the time of our conversation, he receives 'around 100 lats' per month from the state, an amount that only covers a tenth of his expenses, he tells me. He is therefore forced to work. Fortunately, he has been able to retain his job and partnership in a small auto repair firm, dealing specifically with computer diagnostics for cars. He works there every weekday, even on the days that he undergoes haemodialysis, and sometimes also on Sundays. This is possible, he tells me, because his previous transplant is still in his body, which makes him hypertensive. 'It's easy to work with hypertension,' he says. When, in a not too distant future, his non-functioning transplant is taken out and his blood pressure again begins to drop after the treatment, he expects that working as much will become more difficult.

Among the fifteen persons with kidney failure whom I interviewed in Riga, five were able to supplement their sickness benefits with some kind of paid labour. Valda worked at a jewellery store, Egils had his own company, Stanislav was a contractual worker in the construction industry, and Pyotr worked at a sewing factory. The others either relied on support from their immediate or extended family or made do with the little money they received from the state in the form of sickness benefits or pension.

The Swedish health care system, like the Latvian, has undergone a process of neoliberalisation in recent decades, a process that has entailed not just a privatisation and decentralisation of services but also an implementation of policies aimed at increasing patient choice and decreasing patients' dependence on sickness benefits (Axelsson 2000; Anell, Glenngård, and Merkus 2012; Ståhl, Müssener, and Svensson 2012). As Ståhl et al. have shown, for instance, the standardised time limits on the sickness insurance that were introduced in 2008 have made the sick-listed persons themselves increasingly responsible for ensuring that they can stay on sickness benefits or return to work, a development, they argue, that may have 'anti-therapeutic effects' (2012, 1408). Despite these recent developments, however, issues of state support and economic security did not seem to be high on the agenda of the Swedish participants. It was ordinarily only when I posed specific questions about these issues that they were addressed during the interviews.

This was the case in my interview with Marianne, for example. It was only at the very end of our almost two-hour conversation that we began discussing the issues of economic security and working while on haemodialysis. Although she has not worked since 2005, Marianne does not characterise her economic situation as strained. She has calculated that she loses SEK 5,000 every month that she does not work, but says that she would probably manage even without the contribution that her husband's salary makes. Having no children to support (their daughter is grown and lives on her own), Marianne and her husband are even able to save some money at the time of the interview.

Among the Swedish participants, Tomas is the one who describes his economic situation as most strained. He is barely able to make ends meet, he tells me. 'There's no room for any major excesses, I can tell you that,' he says. Like Marianne, Tomas has not worked since 2005. He was forced to quit his job as a security guard with the public transport system in Stockholm when he was diagnosed with diabetes and became dependent on insulin. At the time of our conversation, he is living by himself in a suburb south of Stockholm and is six months away from reaching the age of retirement and receiving an ordinary pension, a prospect that somewhat worries him. For Tomas, it seems, the uncertainty characterising his economic situation is added to the erraticism of his body, making a colonisation of the future even more difficult.

At the time of my fieldwork in Stockholm, none of the persons with kidney failure whom I interviewed were working. Some, like Veronica, had tried to work for a while, but noticed that they could not manage. Others, like Tomas, had been prohibited from continuing to work, due to safety regulations at their workplace. Others were so young when they fell ill that they had not entered the labour market yet.

During my visits to the self-care unit, however, I met a few patients who were working while on haemodialysis. One was Gustav, a man in his forties who worked as a geologist. Due to his dependence on haemodialysis, though, Gustav had had to reduce his working hours to 25 per cent of full-time. After four of his five weekly treatment sessions he went to his workplace and spent two hours there. While this was what he could manage with both time and energy, arranging his week this way also allowed him to 'keep up with' what was going on at his workplace and satisfy his need for social interaction. Since he was hoping to be transplanted soon, and thereby be able to return to his job, he thought it was important to follow the development of the company he worked for and keep in touch with his colleagues. During my fieldwork at the self-care unit, I got the impression that this was the most common way patients combined treatment and work. Not being able to work full-time, the main motive for working while on haemodialysis was to keep one foot in the labour market and maintain a certain sense of normality and continuity in one's life.

The capacity of work not just to improve one's economic situation but also to facilitate one's alignment with pervasive ideals such as activity and independence was evident among the persons I interviewed. '[When you fall ill] you become dependent on the Social Insurance Agency. It's not so fun having to ask for help in that way,' Camilla told me, and continued, 'That's one of the reasons you want to begin creating your own life and become self-sufficient again.'

Thus, even though she manages haemodialysis by herself at home, Camilla is unable to escape the dependence that her reliance on sickness benefits signals. In being unable to fend for herself, she deviates from the normative lines prescribing self-sufficiency and self-actualisation. As Rose has pointed out, in a neoliberal context dependence is increasingly conceptualised as a pathology of individual will, as the result of a person's inability to make autonomous and responsible choices aimed at the realisation of his or her personal desires (1999, 268–269). Rather than being primarily a structural phenomenon, dependence is seen a deficiency in the person. Conceptualised in this manner, Camilla's dependence on sickness benefits is mirrored back on herself, becoming a part of her personality for which she is herself responsible (cf. Sennett 1998; Fioretos 2009).

Interestingly, Rose discusses this new conceptualisation of dependence under the heading '*Technologies of activity*' (1999, 268, emphasis in the original). It is only by aligning oneself with the imperative of activity, prescribing action in the form of self-actualisation, that one may escape the label of dependence, he argues. It is not strange, therefore, that in the absence of a functioning transplant, and in addition to studying and exercising regularly, Camilla contemplates applying for a part-time job. But since haemodialysis 'takes so much time and has to come first', it would be impossible for her to work more than 25 per cent of full-time. In Camilla's own words, the reason she would not mind working part-time is that 'it is good to have something to do', signalling that the doing, the activity, itself is important. Thus, even though, in her mind, she will not be able realise her desires and dreams until she is transplanted, working a little every week would bring her closer to an alignment with the lines of activity and independence.

A similar notion of the normalising capacity of work is present also among the persons with kidney failure in Riga. Although Pyotr's main motivation for working while on haemodialysis is to provide economically for himself and his family, it is evident that his having a job is essential for his ability to describe himself as an 'absolutely normal person' on the days between the treatment sessions. Besides the absence of illness symptoms, it is the fact that he works on the days without haemodialysis that enables him to align himself with the notion of normality (cf. McKevitt, Luse, and Wolfe 2003; Crowley-Matoka 2005).[63]

As this section has shown, falling chronically ill and becoming dependent on invasive medical therapies affects one's economic situation. There is thus an intimate relationship between a person's health and his or her financial situation (cf. Ståhl, Müssener, and Svensson 2012). But the degree to which this is so varies. In Latvia, where the social support provided is highly insufficient, persons who fall ill with a chronic condition tend to be thrown into a deeper economic vulnerability than their fellow sufferers

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[63] Cf. the sub-section 'First-level bodily processes' in this chapter.

in Sweden. A way to remedy this vulnerability is to work, which the Latvian participants in this study do to a greater extent than the Swedish. But as we saw, working may also have a normalising effect, bringing a person closer to an alignment with such pervasive ideals as activity and independence.

Summary of the chapter

In this chapter I left the immediate context of the haemodialysis practice and conducted an extensive exploration of the life persons undergoing haemodialysis live when they are away from the treatment unit. I began by giving an in-depth account of three participants' descriptions of their life away from the treatment. On the basis of these descriptions, I argued that the sick body – constituting a continual cultivation of a synthesis between the body-as-subject, the ill body-as-object, and the diseased body-as-object – created by persons undergoing haemodialysis was essential for how they managed living with kidney failure and haemodialysis. In order to grasp the full implications of this, I made use of Zeiler's version of Simone de Beauvoir's concept of the body in a situation. This enabled me to notice that what mattered most in the daily lives of the participants was not the extent to which they were oriented towards their own bodies, but the extent to which the emergence of their bodies, in the form of dys-appearances, disrupted their intentions. Since they had and were continually cultivating a sick body in a situation, they did not take their body and their intentions as two separate intentional objects; the one was intimately intertwined with and coloured by the other. To varying degrees, this enabled the participants to avoid instances of bodily dys-appearance that disrupted their intentions, either by working on their bodies or by reorienting their intentions.

However, persons undergoing conventional haemodialysis and persons undergoing self-care haemodialysis were varyingly capable of doing so. While the latter could work on the treatment itself, enacting a sick body in direct relation to the haemodialysis machine, the former had to subject themselves to the four-hours-three-times-a-week regime of conventional haemodialysis, thereby having to locate their enactment of a sick body in a situation only to their life away from the treatment. Thus, the conditions for avoiding disruptive dys-appearances and for a more general endeavour towards health, towards a sense of homelikeness, varied between the two groups of patients. While both groups were able to live their bodies as personal projects, the self-carers were seemingly more capable of aligning themselves with the morally and normatively charged ideal of health.

But this was only partially so. There were significant temporal dimensions to the bodily processes that commenced when the participants became dependent on haemodialysis. More exactly, there were bodily processes on three temporal levels. On the first level were bodily processes that spanned hours and recurred on a day-to-day basis, not infrequently according to the rhythm of the treatment. On the second level were bodily processes that recurred more seldom and either followed the rhythm of the monthly lab tests or had a rhythm of their own. On the third level were bodily processes that were more or less irreversible and that continuously intensified, at least as long as the person with kidney failure underwent haemodialysis. When these temporal dimensions were taken into account, it became clear that self-care haemodialysis primarily alleviated bodily processes on the first temporal level. Just like their fellow patients in conventional care, the self-carers experienced bodily processes on the second and third temporal levels.

These temporal dimensions had a great impact on the way in which all participants were able to live time. Virtually all of them experienced the future to be beyond their reach. Since they embodied a gradually deteriorating and erratic body, they experienced the future as an uncertain ground over which they could exert little control. Engaging in a self-actualising colonisation of the future was thus practically impossible for them. But the self-carers were able to exercise a certain control of their time in the short term. By means of their ability to determine when and for how long they would undergo the treatment, they experienced a degree of flexibility and independence. This stood in stark contrast to the persons undergoing the conventional version of the treatment, who generally felt that they had lost control over their life due to their subjection to the rigid temporality of the treatment. Thus, while the self-carers were to a certain extent able to align themselves with the ideal of being in control of time, the persons on conventional haemodialysis were not.

All participants, however, experienced a restricted mobility. They felt that their dependence on haemodialysis prevented them from being as mobile as they wished, an experience that was primarily expressed as a frustration over not being able to travel. Since mobility and being able to travel is an essential feature of the autonomous and enterprising individual so praised within neoliberal thought, this frustration was highly normatively charged, I contended. Among the Swedish participants, however, a few had travelled and undergone so-called guest dialysis in another country, but all of them described the process of arranging such trips as laborious and challenging, aspects that made some participants avoid them altogether.

Due to the restricted mobility that the participants experienced in the wake of becoming dependent on haemodialysis, the home became a place where they spent more time than they had before they fell ill. But their homes had changed. Due to the deep intertwinement between body and home, the participants now experienced their home as an ambiguous spatiality, as a simultaneously safe and risky place. On the one hand, the home constituted a safe haven, rather unaffected by disease and medicine. On the other hand, it had become a risky place, containing hazardous spaces and practices, a place that was at constant risk of being invaded by medicine, by treatment technologies and practices, and the symbolism that these carried with them. The latter was particularly evident in the Swedish context, where the ideal of home-based health care was particularly pervasive and present in the form of home-haemodialysis. The majority of the Swedish participants had turned down the offer of managing haemodialysis at home, due to the risks described above. Interestingly, however, the two participants who actually did perform the treatment by themselves at home felt that their previous concerns about the risks associated with the procedure had been largely unfounded.

I ended the chapter with an exploration of the participants' economic situation. Here, an intimate connection between health and economy emerged. Since the majority of the participants were unable to work after they fell ill and became dependent on haemodialysis, they had to rely on social support in the form of sickness or retirement benefits. In Latvia, however, these benefits were virtually impossible to live on, which forced some to work, while others relied on economic support from their family. Still others were forced to get by on the little they received, which created a situation where they were faced with the choice of providing for themselves and their family or buying the medications necessary for treating their condition. In the Swedish context, working while on haemodialysis did not seem to be necessary from an economic point of view; the benefits were low but sufficient. Here, work was instead seen as a way of achieving a normalisation of oneself and one's life, as a way of aligning oneself with the ideals of independence and activity. But this was the case also in Latvia. Here, working was seen as filling a normalising function too.

7. The pragmatic orientation towards kidney transplantation

In this chapter I resume the discussion of kidney transplantation that I initiated in chapter 3. I begin by delving deeper into the dominant discourse surrounding the procedure in an attempt to provide a more comprehensive discursive context to the particular empirical focus that I have here. In chapter 3 I identified a shift in orientation among the participants who had undergone transplantation. While, prior to the procedure, they tended to be oriented along the lines of what I termed the dominant orientation towards transplantation – being quite self-evidently oriented towards it, associating it with powerful values such as survival, health, and normality – following the procedure, their orientation generally shifted, becoming characterised by a great degree of pragmatism and an awareness of the complexities accompanying it. It is this pragmatism and these complexities that I explore in this chapter. My focus is on the stories of those who have undergone one, two, or even three transplantations.

A second look at the dominant discourse on organ transplantation

In chapter 3 I showed how the dominant discourse on organ transplantation accumulated into a powerful orientation, an orientation so forceful that it shaped the information doctors gave their patients and oriented the patients themselves to expect a self-evident return from the procedure in the form of survival, health, and normality. I argued that the reason for the pervasiveness of this orientation was to be found in the joint forces of several powerful processes: the use of organ transplantation as the real-time proof of the capability of medicine to create a completely regenerative body; the imperative of movement that puts patients and caregivers on an unquestionable 'heroic intervention pathway' within the realm of medicine; the technological imperative that makes the application of what is considered to be the state-of-the-art technologies inevitable; and the alignment of the promises attached to transplantation with the ideals of independence, responsibility, and activity advanced within neoliberalism. Paired with the results of the biomedical evaluations of the procedure – confirming the superior survival rate and quality of life of transplant recipients as compared to dialysis patients – the joint forces of these processes construct an image of organ transplantation as a straightforward and self-evident producer of health and normality, I contended.

It is this image, I would argue, that makes possible the current, one-sided focus on the shortage of organs for transplantation (cf. Schicktanz and Schweda 2009, 476; Moniruzzaman 2012, 84). As several scholars have contended (see e.g. Siminoff and Chillag 1999; Sharp 2006; Gunnarson 2012), in the current lay and professional discussions on organ transplantation, the shortage of organs is constructed as the main, if not the sole, problem that transplant medicine faces. The only thing preventing the practice of organ transplantation from realising its full potential is the limited organ supply, not some deficiency in the procedure or technology itself, it is argued. Due to this 'organ scarcity anxiety', as Sharp (2006, 17) terms it, attention is generally oriented away from the 'demand' side of the equation in favour solely of the deficient 'supply'.[64] As a consequence, the demand for organs becomes an unquestionable point of departure for the discussion. 'This one-sidedness', Schicktanz and Schweda argue, 'narrows the ethical scope of debate: once the quantity of donor organs is identified as the central problem, the search for and acceptance of solutions is restricted to strategies aimed at increasing the available "supply", such as financial incentives' (2009, 476; see also Kierans 2011). There is therefore little room in the debate for proposals aimed at reducing the demand for

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[64] The terms 'supply' and 'demand' should be understood here as emic terms, that is, terms that originate from within the empirical field itself. When the shortage of organs is discussed, in lay as well as professional contexts, economic terms such as supply and demand are often used.

organs – through preventative measures, for example – and for voices that address the ways in which the medical community itself is complicit in enhancing the demand by deeming an increasing number of patients eligible for transplantation (Scheper-Hughes 2000, 2003; Sharp 2006, 18; Bagheri 2007).

In the dominant discourse on organ transplantation, instead, the focus on the shortage of organs persists. The shortage causes desperation among persons with organ failure, it is said, persons who 'die while waiting' (Matas 2004, 2007) for these 'desperately wanted goods' (Radcliffe-Richards et al. 1998, 1951). This conceptualisation of the problem has spurred the advancement of a vast array of more or less innovative proposals on how to increase the supply of organs, some of which have already been implemented in a number of countries. Among these are proposals for expanding the medical criteria determining who qualifies as a brain-dead donor; introducing an opt-out system in which citizens are required to actively express their will not to donate after they die; using so-called non-heartbeating donors – patients who will most likely die when their life support is turned off but who will not meet the criteria for brain death; and expanding the criteria under which living donation may be performed (Sharp 2006; Pascalev et al. 2013). But during the last decade the most common proposal has become the implementation of financial incentives for donation, the introduction of a regulated market in organs being the most heatedly debated (Sharp 2006, 18). At this point, only Iran has introduced such a market, but influential actors, especially from within the fields of transplant medicine and bioethics, are arguing for the implementation of a regulated market in organs more generally (see. e.g. Radcliffe-Richards et al. 1998; Friedlaender 2002; Savulescu 2003; Omar, Tufveson, and Welin 2010).[65]

Taken together, these proposals are indicative of the one-sided focus in the discourse around organ transplantation on the short supply of organs.

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[65] There also exists an extensive and illegal trade in organs, in which predominantly poor persons from Third World countries sell their organs to more affluent persons from First World countries, a trade which is mediated by so-called organ brokers. For an overview of the phenomenon of trafficking in human beings for the purpose of organ removal see Pascalev et al. (2013), available at http://hottproject.com/reports/reports.html, accessed 2014-06-13; see also Gunnarson and Lundin (2015) and Lundin (2015).

What happens, then, when a biomedical technology is conceptualised in this manner as a 'victim of its own success' (Ambagtsheer, Zaitch, and Weimar 2013, 3) since it lacks the human material required for fulfilling its life-saving and normalising capacities? As I have argued elsewhere (Gunnarson 2012), and as a number of other scholars have pointed out in their studies of persons living with a functioning transplant (see e.g. Siminoff and Chillag 1999; Crowley-Matoka 2005; Kierans 2005; Sharp 2006), this conceptualisation leads to an understanding of organ transplantation that is ignorant of the complexities and hardships associated with it. When it is framed as a straightforward producer of health and normality held back only by a short supply of body parts, its positive sides are enhanced and promoted, while attention is diverted away from the difficult decisions, medical interventions, transformations of family relations, and suffering that it might give rise to.

Before initiating my exploration of the ways in which these complexities and hardships emerge in the stories of the participants in this study, I want to emphasise the fact that I am not studying organ transplantation in general here. I am studying kidney transplantation, which differs from other forms of organ transplantation in that there exists an effective alternative therapy and in that the exchange of kidneys between living persons constitutes a routine practice. Thus, the biomedical alternatives that persons with kidney failure encounter when they fall ill differ from the alternatives, or lack thereof, that other organ failure patients meet, a fact that quite likely affects their orientation towards them.

For persons with heart and liver failure, for example, there are no alternatives to transplantation that are as effective as kidney dialysis. Since there is dialysis, kidney transplantation is not as acutely lifesaving as heart, lung, or liver transplantation. There is almost always a possibility for persons with kidney failure to return to dialysis. Yet kidney donation and kidney transplantation is included in the shortage debate, and in the image of organ transplantation in general, as a routinely life-saving and normalising therapy. This is itself an indication of the force of the dominant discourse on organ transplantation. With the positive sides of the procedure highlighted, enhanced, and promoted as they are, alternative therapies such as dialysis become constructed as its negative flip side. The result is a rather one-sided image of the two treatment alternatives available for persons with kidney failure, an image in which kidney recipients are portrayed as once-and-for-all saved and capable of returning to a healthy and normal life, while a life with dialysis becomes almost inconceivable, since it is reduced to mere waiting, suffering, and dying (see e.g. Radcliffe-Richards et al. 1998; Monaco 2007; Abouna 2008; Charro et al. 2008; Matas 2008; Omar, Tufveson, and Welin 2010; see also Gunnarson 2012 and Idvall 2007). In the following – by exploring the stories of persons undergoing haemodialysis who have experienced transplantation – I aim to unsettle this one-sidedness and offer an account that is sensitive to the complexities and contingencies characterising kidney transplantation and its relation to haemodialysis.

Embodying a sick body in a situation while transplanted

Receiving the promised return and being aware of its contingency

On some occasions, transplant recipients actually receive the return promised in the dominant discourse on organ transplantation. Or perhaps, rather, they experience a return that enables them to understand and describe themselves as aligned with the majority of the values attached to it. Such experiences and descriptions are essential for the reproduction of the dominant orientation towards organ transplantation (cf. Ahmed 2006, 17). As we saw in chapter 3, organ donation agencies and NGOs rely heavily on transplant recipients' stories about the positive outcomes of the procedure. If it were not for the recipients' willingness and ability to describe and display themselves as healthy, normal, and free after their receipt of a functioning transplant, the dominant discourse on organ transplantation would not be as pervasive as it is.

As Sharp has shown, however, there is often a discrepancy between the accounts of transplantation that recipients give in public and in private. In public settings, they tend to describe themselves as survivors who have experienced a rebirth thanks to transplantation, thereby relegating post-transplant complications to the background. In private and in interviews with Sharp, conversely, they let the hardships of living with a transplant emerge, recounting physical, psychological, and socioeconomic suffering (Sharp 2006, 107–123; see also Kierans 2005, 352–354). In Ahmed's sense of the term, there clearly exists a 'pressure' on transplant recipients to align themselves with the promises attached to the procedure, at least when they are in public settings (2006, 17). Since they have received the 'gift of life', they are not completely entitled to bring up the hardships they have experienced following their receipt of a transplant (cf. Sharp 2006, 108).[66]

Like Sharp, I soon realised during my fieldwork that the interview setting was sufficiently private to allow the participants to give a nuanced account of their experiences of kidney transplantation. This was especially apparent in the stories of those who felt that the procedure had given them the promised return. In the following, I recount two such stories, one in more detail than the other.

At the time of our conversation, Camilla is waiting for her second transplant. The wait is dragging on because her body has developed antibodies as a result of her first transplant. When she returned to haemodialysis after her transplanted kidney had ceased to function, the doctors told her that the waiting time for a second one would be around a year. But they misjudged the situation, and now, five years later, she is still waiting. When I ask her how she felt during the six years that her first transplant functioned, she says, 'Good. Everything was just as usual then. I worked and stuff like that. So it was a huge difference to go from that kind of extremely draining [conventional] dialysis to receiving a transplant. It was a complete turnaround.' But six years later, Camilla suffered a rejection, and within six months she was back on haemodialysis. To a certain extent, she sees herself as responsible for the severity of the rejection. 'I didn't sense it in time,' she says, 'and… then it wasn't possible to stop.' When she receives a second transplant, she tells me, she will be more attentive to early signs of rejection.

Dmitry, who at the time or our conversations has undergone two trans-

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[66] Cf. the section entitled 'Expecting survival, health and normality' in chapter 3.

plantations, describes life with his first transplanted kidney in a vein similar to Camilla's. 'I lived an absolutely normal life,' he says. 'I was admitted to the hospital for the first month, [and then] I was discharged and went to work the next day.' A while later in the interview he adds that transplantation gave him a feeling of 'being an absolutely healthy person, that is, I didn't feel any side effects, nothing'. Nine years later, the transplant ceased to function and Dmitry returned to haemodialysis. This was not a shock for him, he says, because during the entire time he was transplanted he had been having regular check-ups, which had revealed the gradually deteriorating function of the kidney. Dmitry then spent about a year on haemodialysis before he was transplanted again. But this time the procedure was unsuccessful, causing him a lot of suffering. At the time of our two conversations in October 2009 and June 2010, he has yet to admit himself to the waiting list for a third transplant because he feels that he needs to be 'ideally healthy' in order to undergo it.

Camilla and Dmitry both provide descriptions of organ transplantation that align with the dominant orientation towards it. For both of them, the procedure brought about a feeling of health and normality and constituted a 'complete turnaround', as Camilla puts it, from their life with conventional haemodialysis. Yet it becomes clear during our conversations that neither of them has retained a view of kidney transplantation as a self-evidently life-saving and normalising procedure. It is apparent that they have both undergone the shift in orientation that I wrote about in chapter 3. As Dmitry indicates in his story, for him, this shift in orientation had already begun when he was transplanted for the first time. By means of the regular check-ups that he had to undergo, he soon became aware of his body's chronic rejection of the transplant, a process of rejection that gradually reduced the function of the kidney and brought him closer to haemodialysis. Thus, early on in his life with a functioning transplant, Dmitry became aware of the fact that organ transplantation does not constitute a cure and that the normality and health which he experienced at the time were finite. His story does not reveal whether or not this realisation disoriented him, but it does show that, due to the slow pace of the deteriorating function and the regular recurrence of the check-ups, he was eventually able to reorient himself to expect a return to haemodialysis. Due to the repetitive encounters with his own body as a medical object that these check-ups entailed, he was able to incorporate the limited function of the organ into his corporeal schema, thereby creating a sick body capable of reorienting his intentions and expectations in a way that took into account the finitude of the health and normality which he experienced. This was a reorientation, however, that forced him to misalign himself with the dominant orientation towards transplantation.

What misaligned Camilla with this orientation was primarily the acute rejection she experienced after living with a functioning transplant for six years. But it is apparent in her story that she was aware of the limited duration of the transplant and the risk of an acute rejection long before this. For her, though, this awareness was not primarily a result of information given to her by her caregivers about the function of her transplant but was brought about by the unavoidable presence of the immunosuppressive medications in her life. She knew that she took these medications at specific times every day in order to prevent her body from rejecting the kidney, and was therefore acutely aware of this risk. What was more, Camilla had already, prior to the event that forced her back on haemodialysis, experienced a number of acute rejections that she had sensed in time and that had therefore been possible to stop. She was thus very well aware of the risk of her losing her transplant. Even so, when it actually happened she did not, like Dmitry, take it with equanimity. She felt very sad. ‘It wasn’t fun at all,’ she says, and continues, ‘but then I was sent to the self-care unit,’ which, as we have seen in the previous chapters, she learned was a form of haemodialysis that suited her better.

What Camilla’s story illustrates first of all is the force of the dominant orientation towards transplantation and the power of the values attached to it. Despite the fact that the medications she had to ingest every day reminded her of the risk of having to return to haemodialysis, and despite the fact that she had already experienced several rejections threatening to destroy the function of her kidney, she describes her life with the transplant as entirely normal. This indicates that the moral and normative force of the dominant orientation towards transplantation, as well as the desire of transplant recipients to align themselves with it, is strong enough to conceal the complications and anxieties that the procedure gives rise to (cf.

Siminoff and Chillag 1999; Sharp 2006). Before she fell ill, Camilla would most likely not have considered taking strong medications every day and being at constant risk of organ rejection to be aspects of a normal life, but due to the strength of the positive values associated with transplantation through the dominant discourse on it, she was able to disregard these aspects in her description of her life with it.

But, like Dmitry's account, Camilla's story also reveals that – even though she undoubtedly experienced a sense of normality and health when she was transplanted – organ transplantation does not entail an escape from disease and patienthood. It does not constitute a cure that puts an end to organ recipients' struggle with illness and dependence on medical treatments. Rather, it likely reinforces this struggle. An indication of this is Camilla's contention that, the next time she is transplanted, she will pay more attention to her body and go to the hospital at the slightest indication of an impending rejection.

In a similar vein as Kaufman, Kierans argues that it is an inherent aspect of 'medicine's modernist project' to be insistently oriented towards 'endings' and to exhibit 'a linear drive towards resolution' (2005, 354). It is easy to see how such a linear drive and orientation towards endings permeate the dominant orientation towards organ transplantation. Through the promise of survival, health, and normality as straightforward outcomes of the procedure, linearity becomes both the investment required by and the return promised to prospective organ recipients. If, prior to their first transplant, they orient themselves towards the procedure, it is said, they will receive a return in the form an escape from disease and an ability to begin colonising their own future as healthy and free individuals. But as Kierans (2005) has argued before me, and as my empirical material shows, kidney transplant recipients' experiences of the procedure tend to disrupt this linearity. Early on in their life with the transplant they realise that the relative normality and health that they experience is not eternal, that eventually they will have to return to dialysis. And when they do, their orientation towards the procedure has changed; no longer is transplantation the self-evident life-saver, but a procedure that might offer a healthier and freer lifestyle, provided that one accepts the need to continue enacting a synthesis of one's body-as-subject, one's ill-body-as-object, and one's medical body-as-object – that is, a sick body in a situation.

As soon as they have undergone transplantation, Dmitry and Camilla realise that they still embody a sick body, one that will orient them in certain ways and towards which they will frequently have to orient themselves. Rather than having received linearity in the form of an end to disease and a straightforward future-orientedness, they find themselves in a form of circularity in which the return to dialysis is present as a risk or as a slowly approaching certainty. Moreover, since the sick body that they embody is always a body in a situation, shaped both by the worldly circumstances at hand and by the experiences it has sedimented and the objects and skills it has incorporated, the way it orients itself in the world and towards the treatment alternatives is always subject to change. The circularity that kidney recipients experience is therefore always a spiralling circularity, never returning to the exact point from which it once started. This is particularly evident in Dmitry's story where he tells me how his experiences in the wake of his second, failed transplant affected his orientation towards undergoing a third. He says:

> Let's say, if the second kidney had worked for a longer time, I would probably have another view of life. But living with a non-functioning kidney made me feel uncomfortable in life; I was admitted to the hospital many times that year. You are limited in all dimensions: physically, at work, with money, with the opportunity to do your things. An entire year is lost [whistles] if the kidney doesn't work. The only thing with dialysis is that you are bound to a place.

While Dmitry was rather self-evidently oriented towards transplantation before he underwent the procedure for the first and second time, when I meet him in 2009 and 2010 he is much more hesitant towards it. Now, he tells me, a life on haemodialysis may be preferable compared to undergoing a third transplantation, at least for the time being. He characterises the period he is in when we meet as a period of recovery, a phase during which he will attempt to make his physical and mental health as good as possible. Since this period will go on for a longer time – at least three to four years – than the expected waiting time for a third transplant, he is deliberately turning down the doctors' offers to admit him to the waiting list. Only after this period, and 'if the results for having a third transplantation are good [the results associated with the survival of the kidney itself] then maybe I'll go for a third transplantation. But if it looks like it did [before the second transplant], I'll never go for a third transplantation. Then I will without a doubt remain on dialysis,' he says.

The way Dmitry orients himself towards transplantation and haemodialysis at the time of our conversation is mainly due, then, to his experiences in the wake of his second transplant. During the severe post-transplant complications that he experienced, his body constantly dys-appeared, preventing him from orienting himself in line with the lines of health and normality that he had hoped to follow, and forcing him, in the end, to reorient himself in relation to the two treatment alternatives. As the father of a thirteen-year-old son, Dmitry has to be physically present for his family, and be able to support them economically. To once again experience a year of severe complications as a result of a failed transplant would orient him too far away from these abilities, he says.

As Dmitry's story so forcefully illustrates, organ transplantation is a contingent, complex, and multiple phenomenon (cf. Mol 2002; Lock and Nguyen 2010; Gunnarson 2012). It is not, as the dominant discourse would have it, a universally life-saving, health-bringing, and normalising biomedical therapy. Due to a complex set of circumstances – be they bodily, organisational, medical, social, or individual – an organ may or may not begin to function properly in a recipient's body. Moreover, as we saw above and will see below, even when an organ functions properly according to biomedical standards, the recipient may or may not experience the health and normality associated with it. Erratic bodily contingencies and complex situational circumstances affect how a person perceives living with a transplant and the prospect of undergoing yet another.

As both Dmitry's and Camilla's words reveal, due to the force of the dominant orientation towards organ transplantation, it is virtually only the embodied experience of living with a transplant that enables persons with kidney failure to genuinely question the promises attached to it. It is when they begin to live as a transplanted person that they realise that the procedure does not constitute an escape from their sick body and their patienthood. This is when the shift in orientation discussed above and in chapter 3 occurs, a shift that can be gradual or immediate. What this shift entails is a reorientation away from the linearity and universalism characterising the dominant discourse on organ transplantation towards an awareness of the contingent, complex, and multiple nature of the procedure, what I call 'the pragmatic orientation towards transplantation' in what follows. It is the various dimensions and characteristics of the latter orientation that I explore in the next sections. My ambition is to contribute to a more comprehensive and nuanced understanding of what it might mean to live with a transplanted organ in general and renal replacement therapies in particular.

The paradoxes of transplanted life

Unlike Dmitry and Camilla, Carlos never felt completely healthy when he was transplanted. Although the transplant – which was donated to him by his mother – functioned properly and kept him away from dialysis for thirteen years, he was not '100 per cent', as he puts it. When I ask him why, he says:

> Carlos – Well, because you eat these chemicals [the immunosuppressive drugs]. They make your stomach strange and you're a little bit tired, your body isn't as energetic.
>
> Martin – So, your body was there…
>
> Carlos – Yes, exactly, and mentally, I felt mentally affected by the chemicals. I was frequently downhearted and depressed for no reason, and then I started having panic attacks; there was a period of panic attacks. And I feel now, when I don't take these medications, I take almost no medications, that my stomach behaves completely differently. I also feel differently in my head [mentally].
>
> Martin – In a better way or a worse way?
>
> Carlos – No, in a better way, obviously! The medications are strong. They are cell toxins.

Like Sven, Carlos experienced the presence of the immunosuppressive medications in his life as deeply troubling. Not only did he worry about the side effects listed on the leaflet accompanying them – telling me during our conversation that 'obviously you can't eat them when it says that "you can get stroke, you can get that, you can get that, and you can get that; you can get everything!"' – but he also experienced some side effects that affected his feeling of health quite drastically. This has brought him to the conclusion that 'transplantation is not the solution'.

Experiencing the troubling presence of the immunosuppressive medications in his life while he was transplanted thus directed Carlos away from the dominant orientation towards organ transplantation and its conceptualisation of the procedure as a return to health and normality and as an end to disease. The medications and the bodily experiences they brought about made him aware not only of the constant risk of rejection, but also of the risk of acquiring other diseases. This echoes the findings of previous anthropological and ethnological research on the experiences of persons living with a functioning transplant (see e.g. Crowley-Matoka 2005; Kierans 2005, 2011; Sharp 2006, 108; Amelang 2011). The need to take strong medications at fixed times every day and the side effects that these cause make transplant recipients inevitably aware of the fact that they still suffer from organ failure, that organ transplantation does not constitute a cure, a solution.

In its one-sided focus on transplantation, however, this research has failed to identify a paradox that persons with kidney failure are faced with when they receive a transplant.[67] As I have argued elsewhere (Gunnarson 2012), when they fall ill, persons with kidney failure invariably encounter their body-as-toxic. They become acutely aware of the threat that the toxic substances produced in their body now pose to their health. Since their kidneys no longer function, their body is unable to filter out these substances. This is why they have to undergo dialysis. They will die, they are told, if they do not undergo a procedure that replaces their body's capacity to rid itself of toxins. As the previous chapter revealed, this awareness

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[67] Kierans's (2011) article 'Anthropology, organ transplantation and the immune system: Resituating commodity and gift exchange' is to some extent an exception here.

also extends into and becomes a practical part of their life away from the treatment unit. Here, avocados, bananas, and dairy products emerge as potentially toxic, as food products that they have to monitor and limit their intake of.

While they are on dialysis, persons with kidney failure are thus forced to incorporate their body-as-toxic into the sick body that they enact. They have to orient their intentions in a way – undergo dialysis and cut down on their intake of certain foods – that maintains sufficiently low levels of certain toxic substances in their body. But when they then undergo transplantation and immediately have to begin ingesting strong medications that suppress their bodily reaction to the organ, this orientation is disrupted. Suddenly, their life and health hinges not on an avoidance of toxins, but on an ingestion of them. That this is experienced as a paradox is indicated by Carlos's and Sven's emphasis on and preoccupation with the toxicity of the immunosuppressive medications. During my conversations with them, they both return repeatedly to this toxicity. At one point Carlos even describes the medications as 'pure poison'. It is quite likely their previous orientation towards acknowledging the toxicity of certain food products and keeping their body as free as possible from toxins that makes them so aware of the poisonousness of the immunosuppressants. Since they have learned about the damaging effects of certain waste products on their body, the toxicity of the medications immediately emerges for them. This has led Sven to orient himself away from transplantation completely, while Carlos wants to undergo the procedure again even though he no longer sees it as a definite solution to his problems.

Before going into the reasons for Carlos's desire to undergo retransplantation, I want to address another aspect of transplanted life that emerges in his and other participants' stories as well as in the previous research (see Crowley-Matoka 2005; Kierans 2005; Sharp 2006, 108; Amelang 2011). This aspect is closely linked to the ingestion of the immunosuppressants and has to do with the need to take care of the transplant and avoid situations and places where one might incur infections of various kinds. As we saw in the previous section, to a large extent it was the very presence of the immunosuppressive medications in her life that made Camilla aware of the risk of rejection and the need to take better care of the kidney the next time she is transplanted. But more than materialising the risk of rejection in the form of a pill, the medications also – and primarily, as their name indicates – suppress the immune system. As a consequence, transplant recipients are painfully aware of the increased risk they run of contracting viral and bacterial infections such as a cold or tonsillitis, conditions that may, in their case, more easily evolve into pneumonia and eventually cause organ rejection. It is not strange, therefore, that when I ask Carlos if he thought about the transplant a lot when he was transplanted, he says, 'Yes, obviously you thought about it, about how long it would last, that it shouldn't fall ill. As soon as you fell ill you immediately thought it was the kidney, because it was precious to you.' As Carlos's words indicate, being a transplant recipient entails being constantly aware of the fragility of the relative health one enjoys. This is not only an awareness of the danger of exposure to a common virus or bacterial infection; it is also an awareness of the fact that an organ rejection initially shares many of the symptoms of a cold or the flu, generally starting with a fever. Taking care of one's kidney thus entails both trying to avoid places and situations where the risk of incurring infections is large and paying close attention to what happens in one's body when one does get sick. As Carlos's words suggest, the latter may be thoroughly disorienting.

But the former may be almost impossible, especially because it runs counter to one of the normatively charged promises attached to transplantation. When Valda received her second transplant in 2002 it functioned well from the outset and continued to do so for six years. But early in 2008 she caught 'a horrible bronchitis', which her doctors were unable to treat and which later developed into pneumonia. 'Because of this illness, my kidney stopped working,' Valda tells me. She continues:

> You have to take this into account, yes; there are viruses out there. You catch one of them, and it affects the transplant immediately. You have to take this into account, because you can't avoid it. You can't live within four walls, not going outside, nowhere. And I have a job where I constantly meet people.

At the time of our conversation in October 2010, Valda is working at a jewellery store. This is where she worked when she was transplanted. As she points out, this is the kind of job that involves close interaction with other people, and the risk of getting a virus or bacterial infection that a customer carries is therefore substantial. Protecting one's transplant by avoiding infectious diseases is virtually impossible then.

What Valda's account so clearly demonstrates is that aligning oneself with the normatively charged promise of regaining productivity, of being able to work following transplantation, may itself jeopardise the function of the transplant. This is yet another paradox that transplant recipients find themselves faced with. After the procedure they become aware of the fact that the life they had hoped for and that they had been promised, itself constitutes a risk. As Valda's words indicate, this paradox is not confined to the context of work, but extends to life in general. No one can live within four walls, she points out, indicating that this would be required if one wanted to avoid the risk of incurring infections completely. But according to the dominant orientation towards transplantation, no one *should* live within four walls after receiving an organ. Receiving a transplant should entail becoming free again, enabling recipients to regain their mobility and control of time and affording them the ability to 'get back into society', as Omar, Tufveson, and Welin put it (2010, 94). But, as Valda's account suggests, one's alignment with these ideals itself constitutes a threat to this alignment.

Following his transplantation, Carlos tried to return to the firm where he worked before he fell ill, but there were no openings for him there. 'And then', he tells me, 'I thought, "I have an early retirement pension. Why should I go back to work? How long will I have this kidney?" So I wanted to enjoy life, do things I hadn't been able to do: the freedom. And then I went down to Chile and lived there for a while, with my parents.'

When Carlos underwent transplantation in 1997, standardised time limits in the Swedish national sickness insurance had not been introduced yet (see Ståhl, Müssener, and Svensson 2012). Consequently, even though his capacity to work had probably increased following transplantation, his early retirement pension was not terminated. This meant that he could choose not to apply for work somewhere else. It is interesting to note that what lay behind this choice was an acute awareness of the limited duration of a transplant. It was the inevitable end to the improved health that he was then experiencing that motivated him to orient himself away from working life, towards freedom in the sense of doing what he wanted to do and being where he wanted to be. Through his misalignment with the linear conception of organ transplantation as a cure and with the promise of productivity that is also attached to the procedure, Carlos was able to align himself with the ideal of freedom. It is clear that his misalignment with the former was what enabled his alignment with latter, a fact that made the alignment ambiguous.

As we saw in the previous section, organ recipients become aware early on of the limited and gradually decreasing function of their transplant through the regular medical check-ups they undergo. This was the case also for Carlos. When almost thirteen years had passed since he received the transplant, he knew that his transplant would soon cease to function. This was not just a theoretical knowledge that he had gradually incorporated into his situated sick body. In the end, it also became an inescapable physical experience, disorienting him to the extent that he repeatedly sought medical care. 'When I had around 20 to 25 per cent [kidney function], then I had a lot of problems with my blood pressure. I went to the emergency unit several times, since a lot of water had accumulated in my body.' This quote illustrates very clearly the unmistakable presence of medicine in the lives of persons with organ failure even during the time that they are transplanted. They continually follow the deteriorating function of their transplant, measured in per cent, and incorporate this into their sick body in a situation, reorienting their intentions accordingly. As I mentioned in chapter 4, Carlos had asked his sister, in good time before his transplant ceased to function, if she was willing to give him one her kidneys when he needed a new one, and she had agreed. Unfortunately, however, his body had developed antibodies that made it impossible for him to receive his sister's organ. Due to this unexpected turn of events, returning to haemodialysis was a shocking experience for him, the nature of which I have already described in chapter 4. In this respect, Carlos diverges from the majority of the participants in this study, who tend to describe their return to haemodialysis as quite undramatic due to their knowledge of their transplant's gradual deterioration.

At the time of our conversation in November 2010, Carlos is just about to be admitted to the waiting list for a transplant from a deceased person. The main reason he wishes to undergo retransplantation is that he wants to regain the sense of freedom and activity that he experienced the first time. Nowhere to be found in Carlos's story are conceptions of organ transplantation as a cure or a straightforward normaliser and bringer of health. From his embodied perspective, receiving a transplant is a chance at increasing one's sense of freedom compared to living with haemodialysis. Thus, even though he experienced as many as thirteen years with a functioning transplant, at the time of our conversation Carlos embodies a sick body in a situation that makes him rather pragmatically oriented towards transplantation.

Functionality is a multifaceted thing

As we have seen, in the dominant discourse on organ transplantation, the function of a transplanted organ is generally taken for granted. It is the shortage of organs that is the problem, not some deficiency in the transplant procedure itself. The idea is that if all patients who would benefit from transplantation received a donor organ, every one of them would experience a return to a healthy and normal life. This idea is reinforced rather than nuanced when the most frequently used modes of measuring the success of organ transplantation within medicine – survival rate, graft survival, and quality of life – are taken into account. As we saw in chapter 3, the only nuancing effect that these modes of measurement have on the dominant discourse on transplantation is to show that there is an end to function, that transplants do not have eternal survival. But none of these modes of measurement thematise function per se, not even quality of life assessments, since their aim is generally to make a universal claim about the quality of life of organ recipients, not to explore variations within the group (see e.g. Landreneau, Lee, and Landreneau 2010; Maglakelidze et al. 2011; see also Joralemon and Fujinaga 1996). Nor do any of these modes of measurement take into account the variation in and inevitable deterioration of the function of a transplant during the time a person lives with it. In implicitly assuming organ functionality to be static and universal, and in presupposing graft survival, survival rate, and quality of life to be unproblematically translatable to health and normality, these modes of measurement reinforce the idea that the only problem transplant medicine faces is the shortage of donor organs.

This stands in stark contrast to the contingency, complexity, and variability that emerge in my interviewees' stories. We have already seen how kidney recipients who experience few complications during their life as transplanted persons still become aware of the variability and fragility of transplant functionality and of the fact that the procedure does not unequivocally bring about a sense of health and normality. This becomes even more apparent in cases where the transplanted organ functions well enough to keep the recipient away from haemodialysis, but not well enough to bring about a sense of health and normality. What such cases tell us is that transplant functionality is neither static and universal nor distinguishable from the situational complexities of a particular recipient's life.

This was evident, for instance, in Veronica's story. As we saw in chapter 3, the transplant she received in 2003 functioned well enough to keep her away from haemodialysis for two years, but never well enough to bring about a feeling of health. In fact, undergoing transplantation initially threw her into a deeper state of unhomelikeness than haemodialysis did. When, after a month, she was discharged from the hospital, she could not even walk. At home, she began to try, using the walls for support. But she only managed to take a few steps. 'I was so tired,' she tells me. 'I didn't have energy enough to cook, to do anything… I was completely worn out.' Gradually, however, she regained some strength. But she never experienced the health and normality that she had hoped for. After almost two years, when the function of her transplant was almost gone, she hoped that a return to haemodialysis would improve her well-being. Initially, it did not, and it was only when she increased the number of treatments from three to four a week that she experienced an improvement in her condition.

After she was transplanted, Veronica learned that the complications she experienced were due to the disease that had caused her kidneys to fail in the first place. The disease was also attacking the transplanted kidney, the doctors told her. This attests to the contingent nature of organ transplantation. The function of a transplant hinges on the particular bodily circumstances into which it is inserted, circumstances which can be both biological and social. As Crowley-Matoka has shown, for instance, for the mostly poor Mexican organ recipients whom she interviewed, 'the threat of losing coverage, losing access to the medication, and thus losing the transplant itself was very real' (2005, 828).

Veronica's story also attests to the insufficiency of modes of measurement such as survival rate and graft survival in determining the success of organ transplantation. In taking into account merely the duration of survival for both Veronica and her transplant, these measuring methods fail to account for the suffering and disorientation that she experienced while she was transplanted. Due to complex and contingent circumstances, and not infrequently to the erraticism of the bodies involved – the donor's and the recipient's – the ability of the transplant to bring about a sense of health and normality cannot be taken for granted (cf. Gunnarson 2012). Veronica's experiences while she was transplanted have resulted in her adopting a rather pragmatic orientation towards the procedure. She says, 'If they [the researchers] invent a new form of treatment [to prevent her disease from attacking her transplant], they [her doctors] will tell me, and then I think I want to try. But not the way it is now…'

Marianne has had similar experiences. But unlike Veronica, she has decided not to undergo transplantation again. Since her second transplant ceased to function in 2003, she has managed haemodialysis by herself at home. Her first transplant, which she received in 1989, functioned for five years, and her second, which she received in 1997, functioned for six years. But neither of them brought her back to the sense of health and normality that she had expected. They took her off haemodialysis, but did not make her healthy. Speaking about her life with the two transplants, she says:

> You know, I've had a lot of infections, several pneumonias, sepsis… What infections have I had more? I can't remember. I've had a lot of infections and, well, constant urinary tract infections, and antibiotics basically all the time, and that's not so much fun, you know. And then all the medications and their side effects on top of that.

None of Marianne's doctors have been able to give her an explanation for the complications that she experienced during the times she was transplanted. Her own theory is that the disease that caused her kidneys to fail – vasculitis – has attacked her transplants. But she is not sure. What she is sure about, however, is that she does not wish to undergo transplantation again. When she was just about to receive her second transplant, the doctors told her that the donated kidney was a perfect match, calling it a 'sibling kidney'. But since not even such a well-matched organ functioned well, she is convinced that she should continue with haemodialysis. 'I've become like this,' she tells me, referring to her attitude towards transplantation, 'that now when I have it [haemodialysis] at home, and I've worked up a flow with it, I feel like, pshaw!'

Once again we see the shortcomings of medical modes of measurement in assessing the efficacy of organ transplantation. In merely taking account of the duration of, and not the variation in and contingency of, the function of a transplant, they are incapable of explaining why patients such as Marianne choose not to undergo the procedure again. For Marianne the increased survival rate and decreased risk of mortality associated with organ transplantation are no longer relevant. From the perspective of the situated sick body that she embodies at the time of our conversation, home-based haemodialysis is the superior treatment alternative.

The complexities of living donation

The discrepancy between medical modes of measurement and patients' perceptions of the procedure is found also in the context of living-donor kidney transplantation.[68] In the medical literature, kidney transplantation with organs from living donors is generally described as a form of treatment superior to deceased-donor kidney transplantation (see e.g. Lennerling 2004; Kulkarni and Cronin 2006; Pascalev, Krastev, and Ilieva 2013). Nephrologist and bioethicist Antonia Cronin, for example, describes it as the 'gold standard' (2008, 129). From a purely medical perspective this

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[68] Besides kidneys, living persons can also donate sections of their liver and parts of their lungs, pancreas, and intestines (Pascalev, Krasteva, and Ilieva 2013, 28).

description is not unjustified. Living-donor kidney transplantation has proven to result in superior recipient survival rates, graft survival, and quality of life compared to deceased-donor kidney transplantation (Pascalev, Krastev, and Ilieva 2013, 28). These results, Kulkarni and Cronin argue, can be ascribed to the fact that the recipients of living-donor organs tend to undergo transplantation earlier in their disease careers, that the organ spends less time between bodies, and that it is possible to perform thorough examinations of the function of the organ prior to the procedure (2006, 3262).

Despite these apparent advantages, transplant professionals have not always been convinced of the ethical tenability of living donation, since, in opening up the body of a perfectly healthy individual and taking out one of his or her organs, they 'violate the basic moral tenet of their profession to do no harm' (Fox and Swazey 1992, 39). But in the wake of the perpetually increasing 'shortage' of organs, especially kidneys, and on the basis of studies that highlight the low risks associated with live donations (see e.g. Cronin 2008), living organ donation has become a routine practice in many countries. Voices are increasingly heard advancing the argument that this practice should be expanded even more, certainly because it would make more organs available for transplantation but also because it produces superior results (see e.g. Roodnat et al. 2009).

Seen from this primarily medical point of view, the unwillingness among many of the participants in this study to receive an organ from a living person stands out as irrational. If there is a family member, relative, or close friend willing to donate a kidney,[69] thereby enabling the use of a superior form of treatment, there is no logical reason to turn this offer down. However, what this medical perspective fails to take into account is the way the acts of giving and receiving – of which living organ donation consists – are situated in and shaped by complex sociocultural and familial circumstances. I am by no means the first to acknowledge this. Several social scientif-

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[69] In the majority of the countries in the world where living-donor kidney transplantation is performed, living donors are related or in other ways emotionally attached to the recipient. In recent years, however, an increasing number of countries have begun to practice so-called 'unspecified donation' (see Dor et al. 2011), where donors donate to an unspecified recipient who is unaware of the identity of the donor.

ic and humanistic scholars have already addressed the multifaceted and contextual motivations behind the refusal by prospective kidney recipients of the offer of a living-donor transplant (see e.g. Fox and Swazey 1992; Gordon 2001; Lock 2002). I will therefore not conduct a thorough analysis of this theme here. What I will do, however, is give some examples from my empirical material that illustrate the discrepancy on this issue between the medical perspective and the perspectives of persons with kidney failure.

One will notice first of all in taking a closer look at kidney transplantation activities in the two countries studied here that a fairly large proportion of the transplants performed in Sweden are done with kidneys from living donors, while this share is much smaller in Latvia. If we take as an example the year 2010 – during which I was doing fieldwork in both countries – only 3.8 per cent (2 of 52) of the kidney transplants performed in Latvia were done with living-donor kidneys, while in Sweden this share was 46.3 per cent (171 of 369).[70] These numbers have stayed approximately the same since then.[71] The comparatively few living-donor kidney transplantations performed in Latvia can be explained partly by the fact that a formal living-donor programme had been introduced in the country only as recently as 2009, and partly because there is a lack of social security provisions in place to protect donors from income loss and guarantee them sufficient follow-up care. As a consequence, the great majority of my interviewees in Riga had not been asked about their willingness to receive an organ from a living donor, though most were aware of the existence of this form of donation. Conversely, among the persons undergoing haemodialysis in Stockholm whom I interviewed, the majority had been confronted with this alternative, which is not surprising since transplantation with living-donor organs is considered among Swedish transplant professionals to be the preferred mode of kidney transplantation and since a substantial socio-medical infrastructure is in place guaranteeing the donor reimburse-

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[70] See http://www.era-edta-reg.org/files/annualreports/pdf/AnnRep2010.pdf, accessed 2015-09-25.

[71] See http://www.era-edta-reg.org/files/annualreports/pdf/AnnRep2013.pdf, accessed 2015-09-25.

ment of income losses and comprehensive medical follow up (Lennerling 2004).[72]

Despite these differences, I was struck by how similarly many of the Swedish and Latvian participants reasoned when the theme of living donation came up in the interviews. When I asked Sven if he had ever considered initiating a discussion about living donation prior to undergoing transplantation, he said:

> No, and I had my reasons for that. First of all, in that case I would've got it [the kidney] from one of my kids, who are all completely healthy. But I didn't want to bring that up for discussion, because [...] something could happen in their lives that made it necessary for them to have both of their kidneys. And regarding other family members, I have a half-sister, but she was alone with two kids and I couldn't dream of asking that question to her. [...] And then there was my wife, but we never checked if she had a blood type that matched mine, but I knew that she was a little overweight, which makes it [donation] more difficult. And therefore I didn't want that [to receive a kidney from a living person]. The only option I had was to get one of those 'nec-kidneys' [from a deceased person]. I knew that the quality of such kidneys was a little bit lower than the ones from living persons, but I accepted that because I saw the possibility of either getting a transplant or being on dialysis as giving me overtime [a longer life]...

These words can be compared to Yevgeniy's, who described his thoughts and feelings about receiving a living-donor kidney as follows:

> I decided, a long time ago, that I would not accept a kidney from, for example, my wife, or anybody else. I know that it's possible to live with one kidney, but the risk that it stops working cannot be completely eliminated. [...] I wanted my next of kin to live wholesome lives with two kidneys, so that if one of them stopped working, they could go on living with the other one...

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[72] See also http://www.vgregion.se/upload/SU/Omr%C3%A5de%205/Verksamheter/Transplantationscentrum/PM,%20v%C3%A5rdprogram,%20dokument/PM%20Njurtransplantation/Att%20ge%20en%20njure%202015.pdf?epslanguage=sv, accessed 2015-09-25.

Sven and Yevgeniy both decided early on not to opt for a transplant from a close relative. Although Sven seems to have given this option more detailed consideration than Yevgeniy, both of them have clearly thought about it, and it is interesting to note that their respective decisions not to opt for a living-donor kidney are rooted in similar concerns, that is, concerns about the threat to the donor's health that kidney donation entails. Even though they are quite likely aware of the fact that the risks associated with the procedure are fairly low, the very possibility of some future event that would put the donor's health at risk convinces them that they should not accept an organ from a living relative. In his more detailed account, Sven also considers the particular situations the potential donors around him are in. He would not dream of asking his half-sister, for example, since she is a single parent with two kids. This way of reasoning is quite common among my interviewees. Rather than giving primacy to the improvement of their own situation, they carefully consider the aspects of their close relatives' situations, aspects that make them more or less suitable for donation (cf. Gordon 2001, 260).

Added to this is the transformation of the relationship with the donor that the procedure might entail. In the following quote by Hans, the link between this transformation and the impossibility of reciprocating the gift of an organ becomes evident:

> My wife has four sisters and they have offered [to donate], both the sisters and their husbands. […] But then I've said that I won't take from any of them because then this circular thing is formed where, if something happens, if their remaining kidney breaks down, I would feel eternally indebted. It's precisely the fact that I would be eternally indebted [that makes me turn down their offers], because, the way I see it, there are those who would say, 'Hey, I need to borrow a million crowns, go on, sign this guarantor agreement.' 'What the hell? I won't do that.' 'Well, I've given you a kidney. Come on, you have to help me here.' And to not experience that kind of pressure, it's better to go for a 'necro-kidney'.

Even though the dialogue Hans recounts at the end of the quote is a little over the top – which is completely in line with Hans's character – its claim to truth should not be underestimated. Undoubtedly, it is the eternal indebtedness that he would feel towards the person who had donated an organ to him that prompts him not to opt for a living-donor kidney. Further, in asserting that this indebtedness would become acute in the event that the donor's remaining kidney ceased to function, he couples the indebtedness in an interesting way with the risks associated with the procedure. This link echoes the findings of the previous research on this matter, where dialysis patients' reluctance to accept a living-donor kidney has been ascribed both to the risks incurred by the donor and the impossibility of reciprocating the gift (see e.g. Fox and Swazey 1992; Gordon 2001; Lock 2002).

Another aspects that is relevant to address here – which the accounts above have only implicitly indicated – is the relatively minor importance of the shift in orientation towards transplantation, discussed above, for the participants' decision to turn down the offer of a living-donor organ. Sven and Yevgeniy both decided not to opt for transplantation with a living-donor prior to undergoing the procedure for the first time, and when I interviewed Hans, he was still on the waiting list for his first transplant. Thus, even though they have not experienced the contingencies and complexities of organ transplantation, and thereby have not yet become pragmatically oriented towards it, they still turn down the offer of receiving a living-donor kidney. It is evident, then, that the well-being of, and their relationship with, their next of kin trumps the improvement in their own health that living-donor kidney transplantation could entail.

In Veronica's story, however, and to a certain degree also in Carlos's, a shift in orientation towards receiving an organ from a living person can be detected to some extent. When Veronica learned that she would need renal replacement therapies, she immediately asked her husband if he was willing to give her one of his kidneys, and he instantly said yes. In hindsight, however, Veronica believes it was wrong of her to raise the subject and to ask the question. It would have been better, she says, 'to wait for him to bring it up. I think he would've. But… now I know more, you know, about how big the operation is and that it might not be successful… At that point, I was a little impulsive, I was…' 'Why do I think about this?' Veronica asks herself a moment later, and settles on its being because her husband became very sad and depressed when 'his kidney', as she puts it, did not function well in her body. This was difficult for Veronica too. She felt that she was part of the cause of his suffering. It is apparent during our conversation that Veronica does not regret undergoing transplantation with her husband's kidney. What she regrets is that she did not wait for him to bring the subject up himself.

As the above excerpts from my empirical material have shown, the image of living-donor kidney transplantation as the 'gold standard' treatment for kidney failure, arrived at by means of medical modes of measurement, is not capable of taking into account the complex sociocultural and familial circumstances that affect how persons on haemodialysis orient themselves towards it. Not infrequently, these circumstances stand in the way of what, within the dominant orientation towards transplantation, is considered a superior treatment.

Being pragmatically oriented towards transplantation

As we have seen above, the experiences kidney recipients have while they are transplanted tend to make them pragmatically oriented towards transplantation. Even on occasions when they experience the promised return in the form of health and normality, they become aware of its limited duration, fragility, and shortcomings. They realise that organ transplantation does not constitute a complete and final cure; that it is at best a procedure that makes possible a temporary, and occasionally radical, increase in their well-being. This gives rise to a pragmatic orientation towards transplantation, one which is in itself multiple and contextual since it is, in every instance, the result of individual experiences, circumstances, and ambitions. As such, it is made up of lines that are less persistent than those of the dominant orientation towards transplantation, lines that are often simultaneously more precarious and less constraining to follow (cf. Göransson 2012, 26). Depending on the nature of one's experiences while transplanted, one's life circumstances, and one's ambitions for the future, one's pragmatic orientation towards transplantation will manifest itself differently. One may, for instance, like Camilla, desire to undergo the procedure again since one sees it as the means of being able to get on with one's life again, even though one is aware of the ever-present risk of rejection. Or one may have decided, like Marianne, not to undergo transplantation again due to the complications one experienced when one was transplanted and due to the relative feeling of health and normality that one experiences on haemodialysis. In what follows, I explore various dimensions and manifestations of the set of multiple, contingent, and contextual orientations towards transplantation that I term pragmatic.

Proficient comparison of the two treatment alternatives

When I began to analyse my empirical material I was struck early on by the detailed and proficient comparisons of the two treatment alternatives – dialysis and transplantation – that the persons who had undergone one or several transplantations made during the interviews (cf. Gunnarson 2012). It was evident that their shift from being aligned with the dominant orientation towards transplantation to being aligned with the pragmatic orientation enabled them to compare the two forms of treatment on fairly equal terms. In possessing an experiential knowledge of both therapies they had become more adept at taking into account the complex and contextual aspects of both. This attests to the relevance of broadening one's research focus beyond transplantation, of focusing also on the therapies that precede and succeed it, especially in the case of kidney transplantation, where a relatively efficient alternative therapy exists. Here I hope to contribute to the previous research, which has tended to apply quite a narrow focus on transplantation.

Marianne is one of the participants in this study who makes a detailed and proficient comparison of the two treatment alternatives. At one point in our conversation she says, 'It's like intermittent care: sometimes you are treated with dialysis [and] sometimes you are treated with a transplant.' At another point in the interview she weighs the pros and cons of the prospect of undergoing a third transplant:

> It is good, of course, to rest your vessels. They get really exposed on dialysis. So that's of course an argument for [transplantation]. Another argument for [transplantation] is to escape the constraint, to become more mobile. So there are a lot of advantages if you count like that. And then

> there are the disadvantages. And then you have to consider them, and that's what I have done.

The main disadvantage of undergoing a third transplantation is, in Marianne's view, the many risks involved. If she were to undergo transplantation again she would put herself at risk of incurring the infections she experienced during her previous two attempts. She would also have to undergo not one, but two major surgeries. Before inserting the new kidney, Marianne tells me, the doctors would have to take one of her old transplants out, and none of 'these operations are completely risk-free', she says. Added to this are the immunosuppressive medications and their side effects, which are not only unpleasant but may themselves give rise to other, serious conditions. By weighing these pros and cons, Marianne has reached the conclusion that she will not opt for a third transplantation. From the perspective of the sick body in a situation that she embodies at the time of the interview, home-based haemodialysis appears to be the best option.

It is interesting to note how deeply the two treatment alternatives are intertwined and implicated in each other in Marianne's comparison of them. It is to escape the constraint of haemodialysis and to rest her vessels that she would consider undergoing transplantation again, she tells me. Hopes of unconditional health and normality are thus far away. If we linger for a while with the prospect of resting one's vessels, we see how profoundly haemodialysis is implicated in transplantation in Marianne's reflections on the advantages of the latter. As a person undergoing haemodialysis, and especially home-based self-care haemodialysis, Marianne is constantly oriented towards her blood vessels, and specifically the ones that make up her fistula. Not only does she take an active interest in the condition of these vessels, but she is also invariably reminded of their state every time she inserts the dialysis needles into them. Having this awareness is vital since these vessels constitute the link between body and machine; they are the 'safety line', as Camilla put it in chapter 3, ensuring that the sick person may undergo the treatment that keeps him or her alive.

But with this awareness comes the knowledge of the damaging effect of the treatment on these vessels. As we saw in chapter 6, for persons undergoing self-care haemodialysis, the short-term health and normality that they experience is to a certain degree achieved at the expense of their long-term health and normality. Here, the constant use and abuse of the vessels that constitute the fistula are central. It is not strange, therefore, that Marianne mentions the possibility of resting her vessels as one of the main advantages of kidney transplantation. Implicit in this statement, though, is the inevitable end to the function of the transplant, and the return to dialysis. Marianne does not expect transplantation to free her vessels from the strains of haemodialysis, but merely to offer them a limited period of rest. Conceptualised in this manner, kidney transplantation becomes a way not only of escaping the constraints of haemodialysis, but also of improving haemodialysis itself, of ensuring the revitalisation of the blood vessels so essential for its functioning.

But haemodialysis is also implicitly present in Marianne's account of the disadvantages of transplantation. Here her focus is on the risks associated with the procedure. Implicit in this account is her view of haemodialysis as a less risky form of treatment, a view that she shares with several other participants in the study. Among the persons who have already undergone one or several transplantations, the procedure tends to be seen as a major and risky endeavour, while haemodialysis is generally viewed as the safer and more predictable alternative. For example, one of the reasons behind Dmitry's desire to postpone his admittance to the waiting list for a third transplant until he is 'ideally healthy' is the relative health, and its predictability, that he currently experiences on haemodialysis, both of which allow him to structure his everyday life in a way that enables him to work, attend to his family, and take care of his body. Even though undergoing transplantation could improve his well-being even more, he is of the opinion that the associated risks outweigh the advantages, at least at the moment. Referring to the year of complications that followed upon his second transplant, he says, 'On dialysis, I feel much better and have a higher working capacity. With a kidney, if there are complications, you are physically very weak.'

As Dmitry's account indicates, from the point of view of the situated sick body that results from a person's previous experiences of transplantation and haemodialysis, new intentions and ambitions may emerge. The primary goal for Dmitry, at the time of our conversation, is not to achieve a completely disease-free and normal everyday life through undergoing transplantation, but rather to accomplish a functioning life in which he is able to work, attend to his family, and take care of his body, for which haemodialysis is currently the most suitable therapy in his mind.

Sven has reoriented his intentions in a similar manner. While before he underwent transplantation he thought that 'life would […] really open up itself, forever almost' following the procedure, when I meet him in October 2010 he has decided not to opt for retransplantation. At the time of our interview, rather than aiming for the relative health and normality that a transplant might bring, he intends to remain on haemodialysis and try to improve his health in other ways. This is how he describes it:

> Presently I'm very satisfied with this [haemodialysis], with the predictability of the treatment schedule. My problem at the moment is the infection in my leg. I want to get rid of that and I want to get my hip operated on so I can walk, trot along, perhaps exercise a little and be able to drive my own car [Sven is currently in a wheelchair]. Because then my commute here [the haemodialysis unit] would be much easier. I wouldn't be depending on others [to get here], so it would be very convenient. I do my hours here and then I drive away, and I don't have to decide where I'm going except at that very moment.

A while later in the interview, Sven indicates that if he were able to drive, he would probably be going frequently either to his country house or to visit his grandchildren. At sixty-seven, '[I want to have] some fine years with my grandchildren', he tells me. It is evident that Sven's age plays a rather significant role in his attitude towards the two treatment alternatives. It is not only the toxicity of the immunosuppressive medications that orients him away from transplantation; it is also the possibility of living a fairly good life as a pensioner undergoing haemodialysis.

This attests to the importance of acknowledging the contingent and contextual nature of organ transplantation, of recognising the fact that it is not a universally health-bringing and normalising procedure. Not only does it come with risks, side effects, and a limited duration, but it also always enters the life of a particular person, a life where what is perceived as a meaningful existence may not self-evidently align with what kidney transplantation is understood to offer. The above exploration further illustrates that the shift in orientation towards transplantation that ordinarily takes place when a person undergoes the procedure often coincides with a shift in orientation towards haemodialysis. Since the two treatment alternatives are so intertwined with and implicated in each other, the alteration of a person's attitude towards one often results in a shift in attitude towards the other.

Taking into account the uncertainties and multiplicity of organ transplantation

I would like to return now to Dmitry's story, where the uncertainty and multiplicity characterising organ transplantation – for persons who have undergone it – become strikingly clear. As we saw above, to a significant degree it is their awareness of these uncertainties, these risks, that directs former transplant recipients to become pragmatically oriented towards the procedure. In fact, one can claim that it is largely their consideration of the uncertainties that constitutes their pragmatic orientation. For Marianne it is primarily the risks associated with the surgeries and the danger of once again incurring the lingering infections that she experienced during her first two transplants that lies behind her pragmatism. For Dmitry it is mainly the experiences he had following his second transplant that orients him to take a pragmatic stance towards it, but it is also, as we shall see below, the uncertainties of transplant coordination and the multiplying risks associated with every retransplantation.

When a kidney from a deceased person becomes available for transplantation, a transplant coordinator – generally a nurse employed by the transplant clinic – becomes responsible for ensuring that the organ is allocated to the most suitable recipient. This is the case in both Latvia and Sweden. Since the deaths that result in an organ donation are ordinarily unexpected,[73] and since the time an organ spends outside the donor's or recipient's body – the ischemic time, as it is called – affects its function detrimentally, the logistics necessary for effecting a transplant have to be coordinated under substantial time pressure. This is an aspect of the procedure that

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[73] They are typically the result of cerebral haemorrhages or accidental trauma to the head.

transplant recipients typically become aware of when they undergo it, not least because the procedure itself often begins with a sudden phone call telling them to appear immediately at the transplant clinic, but also because, after the surgery, they generally receive some information about the circumstances surrounding the donation. For Dmitry, this awareness, combined with the complications he experienced in the wake of his second, failed transplant, reinforces his desire to postpone his admittance to the waiting list. This is how he describes the contingencies characterising transplant coordination:

> She [the transplant coordinator] calls one person [patient waiting for a kidney] and he has a temperature. Then she calls another one and he has a cough. Then she calls a third person and he's ill. They all fall away. And that's the way the choice is made, independent of whether you are fourth or fifth or tenth on her list. The kidney would probably match the first person on the list best, for him it could probably function for ten years. But it matched me, so they put this kidney in me.

In the interview, Dmitry frames this account as a hypothetical scenario, but it is not unreasonable to believe that he suspects that something akin to it happened when he received his second transplant. Even if this was not the case, his awareness of the contingencies of transplant coordination clearly influences his orientation towards undergoing a third transplant. So too does his awareness of the multiplicity of organ transplantation. Like the majority of the persons who have undergone transplantation and been faced with the prospect of retransplantation among those I interviewed, Dmitry is aware of the fact that the survival rate of a transplant and the chances of finding a matching kidney decrease with every attempt. He even cites a study performed by Russian nephrologists that gives the third transplant a 25 per cent chance of survival. To this is added the increased risks associated with the surgery. 'The third transplantation is a very serious step,' Dmitry tells me. 'It's a longer surgery than the first and second transplantation since the kidney is placed in the centre, under the stomach […]. You need to be ideally healthy at that moment, and the idea needs to ripen in your head.'

Contrary to the dominant understanding of transplantation as the self-evident choice of treatment for persons with kidney failure, from the point of view of Dmitry's situated sick body the procedure stands out as a risky, contingent, and multiple endeavour, something that one does not throw oneself into totally unconditionally. For him, organ transplantation is not a universally health-bringing and normalising therapy, but a variable and uncertain procedure, the success of which cannot be guaranteed and which to a certain extent relies on the physical and mental preparations made by the patient.

Active and passive waiting

One who has experienced the downside of the multiple nature of organ transplantation is Camilla. As I have already mentioned, when her transplant ceased to function in 2006 her doctors told her that the waiting time for retransplantation would be approximately a year. But in making this estimate they failed to take into account the antibodies that had formed in her body, which made finding a matching retransplant much more difficult. At the time of our conversation in May 2011, five years after her first transplant stopped functioning, Camilla is still waiting.

As Kierans (2011) has pointed out, due to its one-sided preoccupation with the supply side of the organ shortage problem, the dominant discourse on organ transplantation conceals the role played by the immune system in the procedure. Claiming that a deficient supply of organs is the only problem that transplant medicine faces relegates the complexities of the matching procedure and the side effects of the immunosuppressive medications to the background, Kierans argues. Stories such as Camilla's, where the waiting time for a transplant is extended due to the reaction of the potential recipient's immune system, are thus rarely heard. Instead, the shortage is advanced as the sole explanation for the long waiting times.[74]

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[74] The existence of a discrepancy between the number of donor organs available and the number of patients deemed to benefit from transplantation obviously makes finding a matching organ more difficult. But even in the event that this discrepancy were eliminated, the complexities of achieving a sufficient match under the time pressure that characterises transplant coordination would remain.

Camilla describes the wait as frustrating. In order not to think about it, she tries to be active, to exercise, study, and hang out with her boyfriend. But it is still difficult. She says:

> You aren't getting any younger. You want to begin to build a life and get an education, which is difficult. I can't study full-time when I do this [haemodialysis], because this has to come first. You don't want to start an education and then interrupt it somewhere in the middle to undergo transplantation or something. You want to be sure that you'll be able to finish what you have started.

Having just turned thirty, Camilla is anxious to give her life direction, to orient herself towards actualising her goals. Unlike Sven, who felt that he could remain on haemodialysis since it would not prevent him from spending time at his country house or visiting his grandchildren, Camilla wants to undergo transplantation since she expects it to restore her capacity to colonise her future and actualise herself. To a certain extent, then, Camilla is still aligned with the dominant orientation towards transplantation; she expects it to bring her back into alignment with the normatively charged line towards self-actualisation. There is much to indicate that what makes this orientation possible, besides her relatively young age, are the positive experiences she had of her previous transplant. As we saw above, even though she experienced an acute rejection after only six years, she describes her life with the first transplant in distinctly positive terms. Thus, the sick body in a situation that Camilla embodies at the time of our conversation does not consist of sedimented experiences that completely contradict a relative retention of her alignment with the dominant orientation towards transplantation.

But she is not completely aligned with it. She no longer sees transplantation as a solution to her problems, and she is acutely aware of the risk of rejection that accompanies every transplant. Like her fellow patients, she offers a proficient comparison of the two treatment alternatives, one that illustrates the multiplicity and variability of both. She says:

> There are advantages and disadvantages with both. I mean, when you're transplanted, there are a lot of medications, and that's not so wholesome. So you have to decide for yourself what you want, if you think it's worth it. For me, it's worth taking them [the medications], because I actually felt very good when I was transplanted. I don't think that, if I get transplanted, the difference will be as big as last time, since dialysis was very hard then [when she underwent conventional haemodialysis prior to her first transplant]. But I will nevertheless, well, [regain] this sense of freedom, I believe, when I don't have to do this [haemodialysis], when I escape the constraint.

Waiting for a transplant is frustrating for Camilla, not because she feels that she is missing out on a medical therapy capable of saving her life and bringing her back to health once and for all, but because she associates it with the possibility of regaining her ability to orient herself towards and shape her own future. In transplantation she sees the possibility of recovering a sense of freedom and normality that haemodialysis cannot offer.

Camilla is not alone in associating organ transplantation with these capabilities. As we saw above, for example, the main motivation behind Carlos's desire to undergo a second transplant was to regain a sense of freedom and activity. But when it comes to Camilla's experiences of waiting for a second transplant, she belongs a minority. The majority of my interviewees, including those who have yet to undergo their first transplant, do not share Camilla's frustration about having to wait for a transplant. This was something that surprised me during my fieldwork.

Among the persons undergoing haemodialysis at the unit in Riga, I soon learned, this absence of frustration could be assigned largely to the fact that until 2007 there was almost no shortage of organs in Latvia. When I asked the surgeons at the transplant unit why this was so, they struggled to find an explanation. They had simply noticed, they told me, that since 2007, the next of kin of persons who were diagnosed with brain death had increasingly not been agreeing to donate their loved one's organs.[75] One

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[75] According to the Latvian law 'On the Protection of the Deceased Body and the Use of Tissues and Organs in Medicine', medical professionals are not obliged to obtain the consent of a brain-dead person's next of kin in order to use this person's tissues and organs for transplantation. It is enough that the deceased has not filed an objection to donation in the Population Register of Latvia (Rozental et al. 2007). However, as Putnina found

theory they had was that this had to do with the financial crisis. But the crisis hit the country in 2008, so it could not account for the decrease in donation that was already happening before this. From 2007 to 2010, they told me, the mean waiting time for a kidney from a deceased donor had increased from seven months to one year. This can be compared to the waiting time in Sweden, which has been estimated at one to three years.[76]

Due to the previously almost non-existent – and during my fieldwork rather short – waiting time for kidney transplantation in Latvia, few of the participants in Riga considered waiting to be a problem. Liouba, for instance, who between my two interviews with her, in October 2009 and January 2010, was both admitted to the waiting list and called to the transplant unit to receive her first transplant – unfortunately, she had a virus infection and could not undergo the procedure – associates being on the waiting list with gaining a sense of hope. Being admitted to the waiting list has made it easier for her to undergo haemodialysis, she tells me, because it signals that she will most likely not have to remain on this form of treatment. But otherwise not much has changed, she says. She even asks herself rhetorically, 'What is this waiting process? You undergo dialysis in the same way. Nothing changes; everything is the same. Every second day you come here for dialysis. There are no preparations; the organ appears very suddenly, that's all…' These words touch upon an aspect of what it is like to wait for an organ that I would like to come back to.

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in her research on the matter, 'transplant specialists did put a lot of effort into discussing donation with relatives of a potential donor' (2013, 342). According to the Swedish Law on Transplantation, conversely, a brain-dead person's next of kin must be contacted and informed of their right to object to the organ donation before the procedure is initiated (see http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/sfs_sfs-1995-831/, accessed 2015-09-23).

[76] See http://www.transplantationscentrum.se/upload/SU/Omr%C3%A5de%205/Verksamheter/Transplantationscentrum/Patientinformation/Att%20ge%20en%20njure%20 2013.pdf?epslanguage=sv, accessed 2015-05-15. The waiting time for a deceased-donor kidney can, however, vary extensively due to, for example, the prospective recipient's blood group, tissue type, and, as in Camilla's case, degree of sensitisation, that is, the level of antibodies in the blood.

First, though, I wish to turn to the Swedish participants' accounts of waiting. Perhaps my empirical basis for making claims about what it is like to wait for an organ in the Swedish context is not substantial enough, considering that only two of my interviewees, Camilla and Hans, were actually admitted to the waiting list during my fieldwork. Eva and Tomas were both hoping to be admitted to the list, but both of them were struggling with contraindications, Tomas with his weight and Eva with convincing a transplant unit in another part of the country to accept her as a transplant candidate despite her affliction with Crohn's disease. Carlos was soon to be admitted to the waiting list, and I will get back to him soon. None of the others, however, were even close to the waiting list at the time of my fieldwork, either because they had decided not to undergo transplantation again – Marianne and Sven – or because they had been deemed ineligible for the procedure – Veronica, Rune, and Bengt. This reflects the fact that only a fraction of the dialysis population in Sweden, and in most other countries, is actually admitted to the waiting list for transplantation.[77]

Unlike Camilla, Hans is not frustrated about having to wait for a transplant. This is because he is not so keen on returning to his job. Before he started haemodialysis in 2007, he worked as a bus driver, and since then his colleagues have informed him about the changes their employer has made in the working conditions. Now, he tells me, the two watchwords guiding the practice are 'efficiency' and 'profitability'. As a result, the well-being of the drivers is not taken into account, he says. On some routes, drivers barely have time to go to the bathroom. On others, their shift ends at some remote station, from which they have to commute back to the garage without pay. The prospect of returning to these working conditions, combined with the fact that he thinks conducting haemodialysis by himself at the self-care unit works quite well, makes waiting for a transplant less difficult. 'Yes, you wait,' he tells me, 'but it's not hard.'

In Marianne's and Carlos's stories, and to some extent in Camilla's, a shift in their experiences of and ways of waiting is detectable. This shift

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[77] For statistics on the provision of renal replacement therapy in Sweden see http://www.medscinet.net/snr/rapporter.aspx, accessed 2015-06-12. For statistics concerning the waiting list for transplantation see http://www.scandiatransplant.org/data/scandiatransplant-figures, accessed 2015-06-12.

largely coincides with, but is only partially due to, the redirection of their orientation towards the two treatment alternatives that takes place in the wake of their first encounter with transplantation. This is how Marianne describes it:

> Marianne – I don't think I had to wait for such a long time, because they prepared me for a long wait. And then it took approximately three years for the first one and three and a half for the second one, and I don't think that's so bad actually.
>
> Martin – So it wasn't something that you kept thinking about and felt impatient about?
>
> Marianne – Well, maybe in the beginning, perhaps when I was waiting for the first kidney. But you become more and more hardened, you know.

So more than being a question of attaining a more pragmatic orientation towards transplantation, becoming less troubled by the waiting can be a result of the hardening of one's character due to trying experiences and to the estimates of transplant professionals about the waiting time. The former is obviously intimately linked to the experiences that result in a pragmatic orientation towards kidney transplantation; one is hardened by the realisation that transplantation does not constitute a cure and a straightforward return to health and normality. The latter is more a category of its own. It is evident in my empirical material that the information about waiting time which transplant professionals give significantly affects the prospective recipients' expectations. In Camilla's story, for instance, the estimate of a one-year wait that she was given has clearly contributed to her frustration. She has now realised that transplant professionals are not in a position to make such estimates, due to the complexities and contingencies involved. 'And I don't think that they should, either,' she says, 'because you get false hopes. And there I was, waiting for a year and nothing happened, and waiting for a year more. Now I don't wait in the same way I did in the beginning since I'm starting to assimilate this [home haemodialysis] into my life more.'

Thus, although Camilla is frustrated about the time it is taking for her to receive a transplant, she no longer waits for it as actively as she did the first couple of years. There are hence different forms of waiting. One can wait actively, which generally involves a thematisation of the actual passing of time. As we saw in chapter 5, the participants tried to avoid this type of waiting by engaging in various activities during haemodialysis. But one can also wait more passively. According to Ehn and Löfgren, longer waits are often characterised by this form of passivity, since they 'make it possible to move in and out of the situation, doing other things, or letting the mind wander' (2010, 76). Quite paradoxically, then, the type of waiting that I describe as passive here both presupposes and facilitates activity. In this form of waiting, it is the waiting itself that is passive, not the person. To describe it in phenomenological terms, the waiting is here an aspect of the person's prereflective bodily being-in-the-world and therefore not actively thematised. But, as Ehn and Löfgren point out, it may suddenly emerge as a problematic aspect of the person's existence, becoming the thematic object of attention. This is probably a quite appropriate description of Camilla's experience of waiting for an organ. She does not constantly count the days she spends on the waiting list, but the waiting occasionally emerges as frustrating when she experiences her life on haemodialysis to be on hold, to be lacking in forward movement (cf. Kierans 2005, 352).

There are thus roughly three ingredients that shape the nature of waiting for a kidney transplant: the hardening and pragmatic reorientation towards the two treatment alternatives that undergoing both of them gives rise to; the estimates that the transplant professionals give; and one's realisation of the impossibility of making such estimates. To give a final empirical illustration of this I want to return to the quote with which this book began, where I ask Carlos to describe his feelings regarding the prospect of being admitted to the waiting list for retransplantation. He says:

> Carlos – Well, I don't think about it that much now. I was so obsessed with the fact that I was going to get a kidney from my sister and that everything would be as usual again, and when that didn't happen, I thought, 'Well, I have to change my attitude. Now only dialysis remains. So now I have to accept that and put up with that'.

> Martin – And how does one do that? How does one manage to do that?
>
> Carlos – [sighs] Well, human beings have the ability to adapt themselves. And then it's also the fact that Swedish health care is still very good. There are such things as self-care dialysis which allows you to have as much dialysis as you want and need, and adapt it to your body. Because now I've had three times a week, and on those three occasions you're supposed to try to get your blood as clean as possible. The result is a very intense treatment, and that's not good for your body. So now when I'm at the self-care unit I can have five times a week and fewer hours, three hours instead of four. So I don't have to go around feeling bad after the treatment. It's gentler. And when I have the machine at home, then I can have six times a week and only do two and a half hours.

And a while later, he continues,

> … I can't adapt to dialysis, it can't be done. I know where my limits are. I know that it's hard to 'take off' a lot of fluid from me. I know that I feel bad after three hours. So I have to adapt dialysis to me. And that's what I'm doing now. To just [go around] thinking about transplantation, if a kidney turns up, well, thank God. But I can't go around thinking about that every day. I gain nothing from that.

In these excerpts, at least two of the ingredients that shape the character of waiting for a kidney transplant are at work. Clearly, in Carlos's view, these aspects make actively awaiting the procedure both senseless and virtually impossible. In accepting the inevitable presence of dialysis in his life and in orienting himself towards adapting the treatment to himself, Carlos is both hardened and pragmatically reoriented in relation to the two treatment alternatives. Combined with the uncertainties and contingencies that characterise the waiting time, this orientation enables him to disregard the fact that he is waiting.

Admittedly, Carlos's disassociation of himself from waiting could be a narrative strategy, considering that few people want to be associated with waiting in contemporary 'Western' societies (Ehn and Löfgren 2010, 27–28). But even though it likely is to some extent, there is much to indicate that, at the time of the interview, Carlos embodies a sick body in a situation that allows him to incorporate the waiting into the prereflective corporeality from which he orients himself. Contrary, then, to the dominant discourse on organ transplantation, in which the waiting caused by the shortage of organs is seen as the main problem, among the participants in this study it is seen as something that can be managed.

Summary of the chapter

In this chapter my main focus has been on the reasons behind and the nature of what I have termed the pragmatic orientation towards organ transplantation. I began by delving further into the dominant discourse on organ transplantation, focusing particularly on the way in which the one-sided focus on the 'shortage' of organs conceals essential aspects of what it is like to live with a transplant, relegating post-transplant suffering to the background and portraying life on dialysis as mere waiting, suffering, and dying.

I then moved on to explore the ways in which the transplant recipients' own experiences of receiving and living with a transplant reoriented them towards the procedure. Even on the occasions that they received the promised return in the form of a sense of health and normality, there were aspects of living with a transplant that made them more pragmatically oriented towards it. Through the recurring medical check-ups and the need to take immunosuppressive medications, the recipients became aware of the contingency and variability of organ transplants. This led me to conclude that the image of transplantation as a universally life-saving, health-bringing, and normalising therapy soon fades away for persons who undergo it. Instead, they realise that they still embody a sick body, one that orients them in certain ways and towards which they frequently have to be oriented. Rather than receiving linearity in the form of an end to disease and a straightforward future-orientedness, they find themselves in a form of spiralling circularity in which returning to dialysis is present as a risk or as a slowly approaching certainty.

That this is so became even more apparent when I explored two paradoxes characterising life with a kidney transplant. Before transplantation, persons with kidney failure struggle to remove toxins from their body. When, after the procedure, they have to begin ingesting a host of immunosuppressive medications, their body emerges as paradoxical. As a consequence, taking the medication, for some, becomes a deeply troubling experience. Another paradox emerged in relation to work. When, after they underwent transplantation, recipients realised that a return to working life could put them at risk of contracting infections that could cause organ rejection, their desire to keep their transplant was posed against the normative promise of a productive life that is attached to the dominant orientation towards the procedure.

What further reoriented kidney recipients to become more pragmatically oriented towards transplantation was their realisation of the variability and contingency characterising the function of a transplanted kidney. This was particularly apparent for persons who had received a kidney that lived up to the medical modes of measuring the success of the procedure but failed to give them a sense of health and normality. This led me to conclude that the medical modes of measurement in use are incapable of taking into account the complexities that determine how patients orient themselves towards transplantation. I came to a similar conclusion regarding living-donor kidney transplantation, which, according to the medical literature, is the ‘gold standard’ treatment but which, from the perspective of the patients, is entangled with complex sociocultural and familial circumstances, occasionally precluding it as a viable option.

I then turned to an exploration of various dimensions and manifestations of the pragmatic orientation towards transplantation. One such dimension was manifested by the participants’ ability to proficiently and pragmatically compare the two treatment alternatives. In these comparisons, they weighed the pros and cons of the two procedures, taking their contingencies and complexities into account, and on some occasions reaching a clear decision about how to relate to them. On other occasions, however, the uncertain and multiple character of transplantation made it difficult to arrive at a definite decision; it was necessary instead, as Dmitry’s story suggested, to wait and see.

I ended the chapter by exploring the thematic that so often accompanies the talk of the shortage of organs within the dominant discourse on transplantation, namely the waiting that patients do. As this exploration illustrated, there are roughly three ingredients that shape the nature of waiting for a kidney transplant: the hardening and pragmatic reorientation towards the two treatment alternatives that undergoing both of them gives rise to; the estimates about the waiting time that the transplant professionals make; and one's realisation of the impossibility of making such estimates. Taken together, these three ingredients make actively waiting for retransplantation virtually impossible. The participants' awareness of the complexity, contingency, and multiplicity of the procedure that emerged through their previous experiences orients them away from actively awaiting retransplantation into a more passive form of waiting, where the work associated with living with haemodialysis takes centre stage.

8. Conclusions

In this thesis I have explored the forms of person- and patienthood enacted and negotiated in haemodialysis and kidney transplantation care and in the daily lives of persons with kidney failure. In doing so, I have paid particular attention to the cultural embedment and normative charge of the studied practices and the forms of person- and patienthood enacted and negotiated here. A basic presupposition of the study has been that contemporary biomedicine is deeply situated in the cultural, historical, economic, and political circumstances provided by the particular local, national, and transnational contexts in which it is practiced. As such, it is both productive and reproductive of pervasive norms, values, desires, and intentions found in these contexts.

In order to explore this multileveled and multifaceted contextual embedment of medicine and patienthood, I located the study in two national settings: Latvia and Sweden, or more specifically, Riga and Stockholm, where I conducted ethnographic fieldwork consisting of observations and in-depth interviews with patients and medical personnel at four haemodialysis units. My subsequent analyses of this empirical material did not presuppose that these two national settings would be relevant units of analysis for all situations and every aspect of the medical practices and daily lives studied. Rather, I took my point of departure in these practices and daily lives, and attempted to discern, from situation to situation and aspect to aspect, when and how cultural processes not just on the national level but also on the local and transnational levels shaped the involved actors' actions and experiences.

Throughout this thesis my primary focus has been the sick persons', and not the medical professionals', perspectives on the issues under investigation. My ambition has been to contribute to a broadening of the social scientific and humanistic exploration of patients' experiences of organ transplantation in particular and contemporary biomedical technologies in general by extending the analysis beyond the very exchange of organs. I have therefore performed a detailed analysis of the practice of haemodialysis and of patients' experiences of living with this form of treatment, as well as of their experiences of falling ill and living with kidney failure.

My analyses of the empirical material have been characterised by what I have termed a cultural phenomenological approach. This approach has allowed me to study the ways in which the intertwinement between body and world implicates and is implicated in the care practices and the everyday lives studied. It has enabled me to highlight and explore the complex interplay between the dynamic character of human embodiment and the cultural embedment and normative charge of renal replacement therapies. It has also allowed me to acknowledge the contextually situated work that persons with kidney failure do in order to existentially and emotionally cope and practically and habitually come to terms with their new situation.

In the sections that follow, I summarise the main findings of this thesis and discuss some of its more general implications.

Encountering the disease and treatments – biomedical lines and embodied experiences

Falling ill entails encountering one's world and one's body as problematic, painful, and to a varying degree alien. It involves experiencing a particular form of disruption of the bodily from–to structure through which one ordinarily orients oneself outwardly towards the objects and others of the world. Due to this disruption, one's body exerts a forceful 'existential demand' that one attends to it; one's body 'dysappears', to use Leder's terminology, which I have utilised throughout this thesis (1990a, 92).

Thus, it is not primarily the 'political requirement that we turn some ways and not others' (Ahmed 2006, 15) that forces us to orient ourselves towards our body when we fall ill, but an alteration in the body itself which makes it emerge for us as a problematic and painful object with a life of its own: as 'alien, yet, at the same time, myself' (Svenaeus 1999, 186). But this does not mean that falling ill is an event that takes place only in the body. As embodied beings, we are inextricably intertwined with and oriented in and by the world. The world we inhabit is from the outset intersubjective, and therefore always already oriented. In order to find our way in this world we orient ourselves along what Ahmed (2006) calls 'lines', which are the accumulation of points of view taken as a product of orientations. By following lines we come to inhabit the world in particular ways, engaging in certain activities and encountering certain objects and others, an inhabitance that is itself productive and reproductive of this world. As such, lines are normatively charged, and our alignment or misalignment with them is not neutral.

Due to this inextricable intertwinement between body and world, and to the ways in which it orients us along particular culturally embedded and normatively charged lines, what happens in our body is not sealed off from the world we inhabit. The first symptoms of illness are therefore not always experienced as such, but as alterations in the world or in the activities we are engaged in. But what we do – how we orient ourselves in the world – also affects how our ill body emerges for us; certain activities may exacerbate or even cause illness, while others may alleviate it. When the process of falling ill reaches a stage where we begin to understand our experiences as illness and start to advance certain interpretations of it – for example, in medical terms as a particular disease – and take certain actions towards it – for example, consulting a doctor – our ill body is still deeply intertwined with the world, not only as something that prevents us from doing what we want to do, but also as something that is interpreted and acted upon by persons with a particular expertise.

Some of the participants in this study fell ill according to a chronology akin to that sketched above; they first experienced illness and then went to see a doctor who established the illness as a particular disease. The majority, however, were diagnosed before they experienced any symptoms of illness, which attests to the increasing capability of medicine to identify disease before it emerges as illness. These participants encountered their diseased body-as-object before their ill body-as-object. The way they experienced this encounter varied. For some it was deeply disorienting. Finding out that they embodied a chronic and life-threatening disease, without experiencing any symptoms of illness, threw them into a state of uncertainty, in which they experienced themselves as neither healthy nor ill or as simultaneously healthy and diseased. Without any experiences on which to base their knowledge about their embodiment of a disease, they lost their orientation in the world.

This attests to the ambiguous nature of diagnoses. Depending on the embodied situation of the diagnosed person, he or she will experience the entry of the diagnosis into his or her life in different ways. On some occasions it might bring about an end to a period of pain and uncertainty; on others it might itself be the source of the pain and uncertainty. Although, from a medical point of view, diagnoses exist to eliminate ambiguity – by categorising, naming, and delimiting bodily dysfunctions and ailments – they do not always succeed in achieving this end.

For some of the participants in the study, however, the diagnosis and the accompanying prognosis quite rapidly accumulated into a line that was possible to follow, despite the fact that they did not experience any symptoms of illness. This was to a certain extent due to the way in which the prognosis facilitated an alignment between the diagnosed person's bodily experiences and the medical predication that the disease symptoms would not appear until a certain point in the future. But it was also due to the fact that the temporal gap that opened up between the diagnosis and the onset of the disease allowed the diagnosed person largely to retain the orientation that his or her life was currently taking. Both of these aspects greatly affected how the diagnosis was received; when it accumulated into a future-oriented line that was possible to follow, its impact on the diagnosed person's life was smaller.

A similar correspondence could not be found concerning the participants' first encounter with haemodialysis, which was the form of renal replacement therapy that all of them met first. Although there existed strong ideals among the medical professionals about the right way to start dialysis, and although many of the patients, at least in the Swedish context, were aligned with these ideals, the majority experienced their first encounter with the treatment as disorienting. According to the medical professionals, patients should start dialysis as part of a planned procedure. They should be both bodily and emotionally prepared and be knowledgeable about the various forms of dialysis that exist, and they should be allowed to make an informed choice between them. But due to the contingent nature of the participants' first encounter with haemodialysis and the fact that the preparatory and participatory measures taken were unable to prepare them sufficiently for entering the treatment unit as patients dependent on haemodialysis for their survival, many of the participants experienced their first encounter with the treatment as deeply unsettling. Despite their knowledge about the chronicity of the disease and the invasive nature of haemodialysis, it was when the treatment was actually initiated that the impact of the disease on their life became graspable for them. It was when they actually experienced the treatment that they realised how radically it would transform their lives.

A similar realisation took place when the participants underwent kidney transplantation for the first time. While prior to the their first transplant they tended to be aligned with what I termed the dominant orientation towards transplantation, their orientation ordinarily shifted after they had undergone the procedure, making them more pragmatically oriented towards it. The dominant orientation towards transplantation, I argued, emanates from a powerful and pervasive discourse portraying the procedure as a straightforward lifesaving, health-bringing, and normalising therapy. It conceptualises transplantation as an 'end game' (Kierans 2005, 345), a cure, as the successful end to a protracted struggle against disease and death. According to this discourse, organ transplantation is a simultaneously miraculous and routine biomedical therapy, held back only by the current 'shortage' of donor organs.

The pervasiveness and power of this discourse, I argued, derives from the joint forces of several influential processes: the use of organ transplantation as the real-time proof of the capability of medicine to create a completely regenerative body; the imperative of movement that puts patients and caregivers on an unquestionable 'heroic intervention pathway' (Kaufman 2005, 104); the technological imperative that makes the application of what are considered to be the state-of-the-art technologies inevitable; and the alignment of the promises attached to transplantation with the ideals of independence, responsibility, and activity advanced within neoliberalism. Paired with the results of the biomedical evaluations of the procedure – confirming the superior survival rate and quality of life of transplant recipients as compared to dialysis patients – the joint forces of these processes produce a discourse that orients the views and experiences not only of those who are directly involved in the transplant practice but also of the public in general.

Prior to undergoing kidney transplantation for the first time, therefore, the participants in this study tended to be quite self-evidently oriented towards the procedure, expecting it to return them to a life characterised by health, normality, and freedom, not envisioning a future reappearance of dialysis in their life. By aligning themselves with, and thereby reproducing, the dominant orientation towards organ transplantation, the possibility of receiving a return in the form of an escape from disease and patienthood emerged for them, an opportunity that was particularly compelling and appealing from their point of view as haemodialysis patients.

Quite soon after they had undergone transplantation, however, a shift in their orientation generally took place. Even in the cases where the procedure was successful and gave rise to a sense of health and normality, there were aspects of living with a transplant that oriented the participants away from a view of it as universally lifesaving and normalising, towards a view that acknowledged its complexity, contingency, and multiplicity. I termed the latter view 'the pragmatic orientation towards transplantation'. What gave rise to this shift was a set of experiences that the participants had while they were transplanted, experiences that contradicted the image of the procedure purveyed through the dominant discourse.

The need to undergo recurrent medical check-ups, revealing the inevitable deterioration of the function of the transplant, and to take strong immunosuppressive medications, signalling the ever-present risk of organ rejection and spurring the emergence of the body-as-toxic in relation to the endeavour to rid the body of toxins in dialysis, were two such experiences. Another was the difficulty of aligning the desire to return to working life with the need to avoid places where the risk of incurring infections was high. For the participants who did not experience a return to a sense of health and normality following transplantation despite the fact that they were living with what, from a medical point of view, was deemed to be a functioning transplant, the shift in orientation was even more apparent.

In such cases, it was evident that the biomedical modes of measuring the success of transplantation were incapable of capturing the variability and contingency characterising transplant functionality and its complex presence in recipients' lives. I came to a similar conclusion regarding living-donor kidney transplantation, which according to the medical literature is the 'gold standard' treatment, but which, from the perspective of the patients, is entangled with complex sociocultural and familial circumstances, which not infrequently precludes it as a viable option.

What characterised the participants' pragmatic orientation towards kidney transplantation was, besides their awareness of the complexities and contingencies involved, their ability and tendency to proficiently compare haemodialysis and transplantation. No longer was transplantation the self-evident treatment of choice for them. Instead, they actively considered the advantages and disadvantages of both treatment alternatives, which they were capable of doing only after they had experienced both. Also characterising the pragmatic orientation was the predominance among the participants of a passive form of waiting for transplantation. While they tended to actively and anxiously await the procedure prior to their first transplant, after they had undergone it and were admitted to the waiting list once again, they tended to thematise and experience their waiting to a lesser extent. Due to the ways in which their experiences of haemodialysis and transplantation had hardened them and to their realisation of the impossibility of predicting the length of the waiting time, the waiting sank into the embodied background of their everyday work of trying to live with haemodialysis.

As a scientifically and technologically infused practice, deeply embedded in particular sociocultural contexts, biomedicine is both productive and reproductive of normatively charged lines along which it orients its patients. These lines shape patients' perceptions and desires and orient them to understanding various biomedical therapies in particular ways. Not infrequently, these lines offer a possibility for persons who have yet to experience illness symptoms or encounter a particular therapy to find ways of managing their embodiment of a disease and the prospect of relying on particular medical treatments for their survival. However, as the findings summarised above illustrate, when these persons actually encounter a therapy, when they experience it bodily and practically, a complexity tends to emerge that was not detectable from the point of view of the lines they previously followed. The emergence of this complexity may be deeply disorienting or may quite rapidly give rise to a reorientation, but it almost invariably – gradually or immediately – misaligns the sick persons with the lines they followed prior to undergoing the procedure. This attests to the force of patients' embodied encounters with medical technologies and therapies. This is a force that immediately undermines universal claims about the nature of a particular disease or therapy and brings their bodily, practical, and contextual complexities to the fore, at least for the sick person him- or herself. In its endeavour to assist and support patients through their first encounter with various diseases and therapies, therefore, medicine should be sensitive and attentive to the force of such embodied encounters and the complexities that arise from them.

Shaping and incorporating a sick body – the coexistence of person and patient

As my analyses throughout this thesis have revealed, while sick persons' embodied encounters with disease and medical therapies tend to orient them away from dominant lines, the experiences they have in such encounters are not decisive for how they will experience and relate to the disease and the medical therapies in the long term. A basic presupposition of this study has been that human embodiment is dynamic, that it is intertwined with the surrounding world in ways that enable it to sediment experiences, habituate actions and practices, and incorporate object, skills, and norms. The corporeal schema from which we orient ourselves in the world is not static, but capable of reorienting itself by making actions, conceptions, and objects prereflective. In this process, repetition is essential. It is by repeatedly performing particular actions, being in certain places, interacting with particular others, using certain objects, and so on that we are able orient ourselves in new directions. Our orientation in the world cannot be separated from the particular world we inhabit. Orientations are 'organized rather than casual' and rely on the repetition of some directions more than others, as Ahmed expresses it (2006, 158).

As this thesis illustrated early on, haemodialysis is a repetitive biomedical therapy. Patients' survival relies on their repeated, frequent, and regular return to the treatment unit and connection to the haemodialysis machine. Even when they conduct self-care, and may introduce a certain degree of variation into the treatment regime, the need to repeatedly undergo the same procedure is a fundamental feature of haemodialysis. As I have already mentioned, it was ordinarily only through their first embodied encounter with haemodialysis that the impact of the repetitive and time-consuming nature of this treatment on their life, and with it the chronicity and severity of the disease, became apparent to them. This realisation spurred the need for finding ways to cope. Among the participants in this study, three interrelated modes of coping were used. Although these were primarily located on existential and emotional levels, they involved the body in fundamental ways. They constituted three interrelated ways in which the participants endeavoured to incorporate their embodiment of the disease and dependence on renal replacement therapies into the prereflective corporeal schema from which they oriented themselves in the world. These modes of coping were also profoundly coupled with pervasive normative orientations in contemporary neoliberal culture, such as positive thinking and the cultivation of acceptance in the face of overwhelming risks.

Although they were primarily located on an existential and emotional level, the three modes of coping were intimately intertwined with the participants' practical engagement with and experiences of undergoing haemodialysis. In fact, these two levels were to a large extent mutually dependent, which became particularly apparent when the repetitive nature of haemodialysis was brought into the equation. As my analyses illustrated, the repetitive character of the treatment was not only something patients had to learn to existentially and emotionally cope with, but was also itself an aspect of the treatment that made their coming to terms with and getting used to it easier. Through their frequent and regular return to the treatment unit, and their repeated and intimate interaction with the haemodialysis machine, the patients habituated and made routine several dimensions of the treatment: the spatiality of the unit, the treatment technologies, and the actions carried out and events taking place in the course of the treatment. As a result, these dimensions were relegated to the background of their attention, becoming familiar aspects from rather than towards which they were oriented. This led me to conclude that the repetitive nature of haemodialysis gave rise to particular forms of patienthood.

Beginning in the conventional version of the treatment, I realised that the close interaction between patients and nurses that took place there, at least at the beginning and end of the procedure, combined with the habituation of the treatment setting and practice resulting from the patients' recurrent returns to the units, was essential for the form of patienthood enacted. Due to the frequency and regularity with which the nurses and patients interacted, they became familiar with each other. This familiarity together with the mundaneness of the actions they performed made the constant enactment of the patient's body-as-object essentially unproblematic. Even though the nurses' hands were constantly treating and constructing the patient's body as a medical object, neither of the involved actors had to direct their attention towards it. On the occasions that they did, the patient's body-as-object emerged as a habitual intermission in their otherwise personal exchange.

This led me to conclude that, contrary to the contention of numerous social scientific and humanistic scholars, the objectification of the human body that takes place in medical practice is not always detrimental to the sick person. Under some circumstances it may be made innocuous and absent; under others it may become – as my analysis of the mode of coping called 'the body without kidneys' revealed – a thematised object that extends the sick person's reach, allowing him or her to initiate a reorientation of his or her life. What is essential, I argued, is to take into account the contextual and situational circumstances under which the objectification of the sick person's body takes place.

In the context of conventional haemodialysis, situations did occur when the patient's body-as-object emerged as problematic. This tended to happen in instances where a misalignment between the body-as-subject, the ill body-as-object, and the diseased body-as-object took place, which resulted in a disruption of the habitual character of the actions underlying the treatment practice. Such misalignments could be the result, for example, of differing views on the cause of a bodily reaction or of the non-conformity of embodied experiences and medical claims. On such occasions, the patient's body-as-object emerged as a contested object, the meaning of which was ordinarily determined by the medical professional – much due to the asymmetry characterising the medical encounter. Unsurprisingly, this also affected the relation between the sick person and caregiver. Rather than interacting as persons familiar with each other, and discussing non-medical things, they emerged as nurse and patient for each other.

When such misalignments did not occur, however, the interaction of patients and nurses was often of a personal nature, allowing them to extend as persons into the space of the unit. The enactment of this personhood was both a precondition for and an outcome of the habitual incorporation of the medical body-as-object that took place. This led me to conclude that the practice of conventional haemodialysis enables patients to be both persons and patients when they undergo the treatment.

So too does self-care haemodialysis. But self-care patients' ability to extend into the space of the unit as persons did not hinge primarily on their personal interaction with the nurses, but relied mainly on the temporal flexibility with which they underwent the treatment, their extensive mobility and activity while doing so, and the personal ways in which they managed the technologies. Compared to patients undergoing conventional haemodialysis, self-carers had more opportunities to extend as persons into the treatment spatiality. Due to their proficiency and active engagement with the haemodialysis technologies, they also, to a certain extent, took on the role of medical professionals. From the perspective of the patients themselves, this ambiguous embodiment of multiple identities did not seem to be problematic. But for the nurses it sometimes was; some of them felt that it risked undermining the stable ground on which their professionalism and authority rested.

What further set the self-carers apart from their fellow patients in conventional haemodialysis was the ability of the former to create and incorporate a 'sick body' during the treatment. A sick body, in my definition of the term, is a synthesis of body-as-subject, ill body-as-object, and medical body-as-object. Such a synthesis cannot be taken for granted since the emergence of the ill body-as-object entails its gradual alienation from the sick person's embodied self, and since the medical body-as-object is a standardised and universalised object that does not self-evidently map onto the sick person's experiences. Thus, a synthesis has to be created and, due to the changeability of body and world, constantly cultivated. Neither medicine nor the sick person can achieve it in isolation; the creation of a sick body relies on an intimate interplay between them both, in which the sick person is the most central actor.

The idea, currently gaining in popularity within and beyond medicine, that sick persons should be regarded from the outset as experts on their own body, is therefore misguided. From a phenomenological point of view, as embodied beings, we do not primarily have knowledge *about* our body, but we understand the world and ourselves *through* it. When we fall ill, our body does emerge as an object that we can have knowledge about, but this is an altered body – in the case of kidney failure, a radically altered body – which does not map onto the corporeal schema we currently embody. Such an alignment can be achieved, but it is never complete and is always subject to change. It is furthermore created and cultivated by and from the perspective of the embodied sick person him- or herself, an embodied perspective that gradually changes as he or she begins to incorporate the synthesis of which the sick body consists. Eventually, it is from the perspective of the sick body itself that this synthesis is cultivated. If and when chronically ill persons become experts *on* their body, this expertise is always exercised *with* and *through* this body, an ability that is gained only as a result of the work that goes into synthesising and incorporating the body-as-subject, the ill body-as-object, and the diseased body-as-object. Rather than seeing patients as experts from the outset, medicine should give patients time to create a sick body and function as an educated and perceptive partner in this endeavour.

As my analysis of the practice of self-care haemodialysis revealed, the self-carers' ability to operate and affect the workings of the treatment technologies, combined with the influence they exercised over the timing and duration of their treatments, enabled them to create and cultivate a sick body while they underwent haemodialysis. This was generally not possible for the persons undergoing the conventional version of the treatment, who had to subject themselves to the treatment regime of four hours three times a week and rely on the nurses to operate the machine for them. When they were away from the haemodialysis unit, however, these persons created and cultivated a sick body too. In the context of their daily lives, and through their habitual encounters with their diseased and ill body-as-object, they were able to enact and incorporate a sick body that enabled them to reorient their intentions in ways that allowed them to avoid severe bodily dys-appearances.

For self-carers and conventional patients both, the sick body from and towards which they oriented themselves was a body in a situation, in Zeiler's (2010) sense of the term. It was a body that was inseparable from the particular situation they were in, which meant that when they oriented themselves towards it, they also directed themselves outwards, towards the world. From this embodied perspective, their intentions and their body did not emerge as two intentional objects, but as deeply intertwined and implicated in each other. This enabled them, to varying degrees, to work on their bodies and reorient their intentions in ways that allowed them to avoid instances of bodily dys-appearance that disrupted their intentions.

But the conditions for doing so and for a more general endeavour towards health varied between the persons undergoing conventional haemodialysis and the persons undergoing self-care haemodialysis. The latter generally did not, like the former, have to reorient their intentions to align with bodily reactions occurring immediately after the treatment; feel as if their life was divided into two, into days with and days without haemodialysis; and experience severe overhydration, drastic blood pressure drops, or treatment-associated fatigue. Due to their ability to create a sick body in direct relation to the treatment, the self-carers could mitigate the impact of most short-term bodily processes spurred by the treatment. But when I broadened the perspective to include more long-lasting and less frequently occurring bodily processes not directly linked to the rhythm of the treatment, this difference disappeared. It was clear that the self-carers' proficiency with the machine ordinarily did not enable them to avoid disruptive dys-appearances caused by erratically recurring and perpetually intensifying bodily processes, and this led me to conclude that it is necessary to nuance the often-heard claim that self-care is self-evidently health-improving. Health is not just the absence of treatment symptoms, but, as I have argued throughout this book, a general sense of being at home in the world.

The haemodialysed life – pervasive norms and national differences

Haemodialysis, especially in its conventional form, is a standardised treatment. Its practice is founded on a view of the human body as a universal object that can be treated and cured by means of the same methods irrespective of time and place. This is reflected not least by the fact that the vast majority of haemodialysis patients in the world undergo the treatment three times a week, four hours at a time. Due to this temporal standardisation, haemodialysis affords patients' lives a particular rhythm, a rhythm that penetrates deeply into their lives. Not only is the treatment demanding and draining, causing a set of distressing side effects, but it also requires patients to leave their home and spend extended stretches of time at a hospital unit, the spatiality of which is also highly standardised. In this setting, their body is enacted as a particular medical body-as-object, emerging in quantified and functional terms in the form of blood pressure, levels of various substances in the body, dry weight, KtV, and so on. This medical body-as-object does not remain within the confines of the hospital unit but follows patients home, reorienting their intentions in their everyday life. This is particularly evident in the way in which persons undergoing haemodialysis are required to uproot and intervene in some of their most deeply habituated routines, having to monitor carefully how much they drink and what they eat.

Considering this standardised nature of conventional haemodialysis in particular, and the vast impact it has on patients' lives, the fact that the Latvian and the Swedish participants in this study provided quite similar descriptions of their life with the treatment is not so surprising. As my analyses illustrated, the differences between Latvian and Swedish patients' experiences of undergoing and living with haemodialysis were not infrequently smaller than those between conventional patients and self-carers. It is thus possible to claim that the practice of conventional haemodialysis to a quite significant degree results in a form of transnational patienthood. This is a form of patienthood that extends deep into the patients' personal lives, confronting them with similar challenges and compelling them to reorient themselves in similar ways. To some extent, what is created is a transnational, haemodialysed life.

This is a statement that requires qualification, however. Not only are there a few substantial differences between undergoing haemodialysis in Riga and undergoing haemodialysis in Stockholm – which I will come back to – but the similarities detected must also be seen in the light of the more general commonalities that exist between the two geographical locations. Even though the standard of living differs quite greatly between Riga and Stockholm, the two cities are both capitals of EU member states, countries that have undergone similar processes of neoliberalisation during the last two decades. In the context of health care provision, the two countries have implemented similar reforms oriented towards decentralisation, privatisation, and a strengthening of the role of the patient. In both national contexts, persons in need of renal replacement therapies are guaranteed subsidised medications and free access to dialysis. In addition to the standardised nature of conventional haemodialysis, such similarities underlie the emergence of the transnational, haemodialysed life detected in this study.

An important contributing factor to this transnational, haemodialysed life was the presence at the haemodialysis units in both Riga and Stockholm of the neoliberally influenced ideal of the 'new', autonomous, responsible, active, knowledgeable, and empowered patient. Although, at the unit in Riga, this ideal was in many ways yet to be realised, the notion that a 'good' patient is a knowledgeable, active, and participating patient was clearly detectable. This was evident, for instance, in the assertion by one medical professional that patients should encounter renal replacement therapies in a way that allows them to choose the therapy that best suits them. They should be informed and prepared so as to allow them to make choices that align with their planned, future activities. In the context of the haemodialysis units in Stockholm, the ideal of the 'new' patient was particularly evident in the drive towards self-care. By putting patients in control of their own care and freeing them from their dependence on others, it was argued, self-care improved their health.

When I listened to the participants' stories, it was apparent that the ideals orienting the new patient were not confined to the realm of medicine. It was not only in their role as patients that they were supposed to be active, independent, healthy, and in control, but also in their personal lives away from the treatment units, a finding that attested to the fundamental cultural embedment of contemporary biomedicine and its productivity and reproductivity of pervasive norms and values present in local, national, and transnational contexts. As my analyses revealed, medicine as an institutional practice is not sealed off from the rest of society, and neither is the patient from the person, and the hospital from the home. Rather, there is an intense interplay between them, an interplay that has fundamental bodily, practical, material, and symbolic dimensions and repercussions.

Yet, the participants' bodily and practical alignment with these ideal orientations could not be taken for granted. In fact, achieving a sense of normality was a constant struggle for them – for some more than others, and in relation to some norms more than others. By virtue of their active engagement with the treatment technologies, the self-carers were able to achieve a relative alignment not only with the imperative of activity, but also with other pervasive norms, such as control, independence, and flexibility, which led me to conclude that the particular form of activity that self-care haemodialysis relied on and reproduced was simultaneously normative and normalising. Due to its alignment with the ideal of the new patient and to some extent also with the more general, neoliberal imperative of activity, prescribing actions aimed at self-actualisation, the self-carers' activity became visible as such. This was generally not the case for the persons undergoing conventional haemodialysis, whose activity was not infrequently overlooked.

This is but one example of how norms orient us to acknowledge some ways of inhabiting, experiencing, and describing the world rather than others. Other examples of this that emerged from my empirical material were the ideals of freedom and health. The neoliberally infused ideal of freedom permeating the dominant discourse on organ transplantation prescribed a freedom from as well as a freedom to. According to this ideal, merely enjoying the freedom from the constraints of haemodialysis following transplantation was not sufficient; one also had to display freedom in the sense of a pursuit towards self-actualisation, through regaining one's productive and reproductive capabilities, for example, and one's ability to colonise the future. The ideal of health was also tied to a set of pervasive norms. The improvement of haemodialysis patients' health was seen to rely heavily on their increased control over and active engagement with the treatment as well as the level of autonomy they displayed in relation to their caregivers. By being normatively charged in this way, freedom and health were narrowly associated with certain ways of inhabiting the world.

It was evident that activity, freedom, and health constituted three normative clusters that accumulated into narrow lines, in Ahmed's sense of the term, that were difficult for persons with kidney failure to follow. What made this particularly problematic was the fact that the participants' desire and efforts to be active, free, and healthy also had deeply existential and situational roots. Their endeavours towards becoming more active and regaining a sense of health were aimed not only at achieving an alignment with norms, but also at strengthening their connection with the world as such. From the phenomenological perspective that I employed throughout this book, an embodied person's meaningful inhabitance of the world relies on his or her active engagement with it, meaning-giving actions that are both productive and reproductive of his or her health, understood as a homelike being-in-the-world. The participants' desire to be active and healthy was thus fundamentally existentially rooted. But it also stemmed from their particular embodied situation. Activity emerged from the need, for example, to avoid thinking harmful thoughts and enact a sick body, while the endeavour towards health was rooted in the regularly recurring bodily dys-appearances and feelings of unhomelikeness that the participants experienced. The desire for freedom also had a situational basis, stemming from the spatiotemporal boundedness the participants experienced while they were on haemodialysis.

In their existential and situational forms, the participants' activity, health, and feelings of freedom did not always align with the normative lines orienting these phenomena. Being active in order to avoid harmful thoughts, experiencing relative health on conventional haemodialysis, or feeling free as a consequence merely of one's escape from dialysis did not automatically align the participants with these ideals, which occasionally meant that their activity, freedom, and health were not acknowledged as such.

There were a number of ways, however, in which living with kidney failure and depending on renal replacement therapies differed between Riga and Stockholm. The most obvious and thoroughgoing difference was the varying economic circumstances under which the sick persons in the two countries lived. While the vast majority of the Swedish participants characterised the sickness benefits they received from the state as sufficient, the Latvian participants described their state compensation as highly insufficient. This was not strange since the amount per month that the latter received was generally below the 'survival minimum' defined by the Latvian state. These varying economic circumstances significantly affected the participants' life with haemodialysis. While the Swedish participants generally seemed able to relegate economic issues to the background of their attention, for the Latvian participants economic hardship was a defining feature of their existence, provided that they were not able to work while undergoing haemodialysis. Either way, for the latter, economic concerns made their endeavour towards health more difficult. For those who worked, however, holding a job offered an opportunity to experience a sense of normality, able as they were to come closer to an alignment with neoliberally infused ideals such as activity and independence. Conversely, some of the Swedish participants felt that their dependence solely on state sickness benefits oriented them away from a desired sense of normality.

Varying economic conditions combined with differing policies of privatisation also underlay the presence at the haemodialysis units in Stockholm of expertise other than the purely medical and the absence of such expertise at the unit in Riga. While Swedish patients were in regular contact with dieticians, physiotherapists, and social workers with a counselling function, the Latvian patients had to pay out of their own pockets to get access to such expertise, something few of them could afford. A lack of economic resources was also, according to one of the physicians, what lay behind the general inability of the Latvian nephrologists and transplantation surgeons to provide their patients with sufficient information. However, since the patients at the unit in Riga did not seem to expect to be sufficiently informed by their doctors, I ascribed this lack of information also to the relatively short time that had passed since the fall of the Soviet Union and the dismantling of its profoundly paternalistic health care system. As I discuss elsewhere (see Gunnarson 2015), unlike the Swedish patients, who relied primarily on their caregivers for information, the Latvian patients often relied on each other.

The temporal structure of haemodialysis and its impact on the lives of persons with kidney failure

This concluding chapter has already touched upon the theme of temporality. It has described the simultaneous reorientational and potentially disorientational forces inherent in the repetitive, time-consuming, and standardised nature of haemodialysis. But it has yet to discuss the tension between these forces and the resulting emergence of time as ambiguous for persons undergoing haemodialysis.

If time was not already an issue for the participants in this study before they encountered haemodialysis, following the initiation of the treatment, it was. At this point, their life not only took on an entirely new rhythm, but they also had to find ways of handling the uneventful time they spent connected to the machine, the time alone they spent at home, and their inability to colonise the future. Simultaneously, however, their very ability to find such ways, to initiate a reorientation, was itself grounded in the temporality of haemodialysis. Due to the repetitive rhythm of the treatment and the vast amount of time they spent at the haemodialysis unit, the participants were able to habitually incorporate, to make familiar and routine, several dimensions of the treatment and their life with it. The temporal structure that haemodialysis afforded life was thus, quite paradoxically, both a blessing and a curse for the participants.

In order to understand why this was so, one has to attend to the intertwinement of time with body and space. It was because they embodied an ill body that they had become dependent on a biomedical therapy giving their life a completely new rhythm; and it was the fundamental erraticism of this body that deprived them of their future-orientedness. But due to the dynamic character of their body, their new way of temporally inhabiting the world could become beneficial for them, enabling them, for example, to enact a sick body and get used to spending so much time in a medical environment. The fact that they returned to the same spatial context every time they underwent haemodialysis was also essential in this process. To a great degree, it was their repeated return to the same treatment unit and their interaction with the same objects and others that made a habitual incorporation possible. But this repeated return also gave rise to a strong sense of confinement among the participants, a sense of being bound in space and time, of not being able to move as widely and freely as they desired.

Despite this fundamental intertwinement of time, body, and space, there seemed to be a quality to the temporality of living with haemodialysis that made it particularly difficult to handle. With time, or perhaps, rather, by means of time, the participants were able to create, orient themselves away from, and habitually attend to their own body as a situated sick body and the spatiality of the haemodialysis unit as a familiar and routine environment. To a certain extent, this also applied to the temporal structure of their life. With time, the participants were able to develop ways of orienting themselves away from their inability to colonise the future and from the very passage of time during the uneventful part of the treatment. This ability, however, hinged on the way they bodily and spatially inhabited the world. In order to relegate their inability to be future-oriented to the background, the participants tried to live in the present, which they did by directing their attention towards the daily practicalities of living with haemodialysis and by acknowledging the erraticism of their sick body. What enabled them to orient themselves away from the passage of time during haemodialysis was their engagement in various, carefully selected activities, which involved the use of particular objects and which allowed them to enact a kind of private zone within the confines of the treatment unit.

Despite this, time regularly emerged as problematic and disorienting. The participants often found the very emergence of time into their attention, unlike the emergence of their body-as-object or the spatiality of the haemodialysis unit as a hospital environment, to be particularly difficult to cope with. When, during the uneventful middle part of the treatment, they were unable to engage in any activities – due to a lack of energy, for example, or an inability to concentrate – they became acutely aware of the passage of time, an experience that opened up great existential depths since it made them aware of their fragile state of being. Similarly disorienting was the loss of control of time that many of the participants experienced in the wake of the entry of haemodialysis into their life. Due to the standardised temporal rhythm of the treatment, they were no longer in charge of their time. As a consequence, some of them even asserted, they had lost control of their entire life. I ascribed this close linkage between time and life to the pervasive neoliberal ideal of self-actualisation, in which the capacity to construct a desirable orientation for oneself towards the future is essential. While the self-carers were able to regain a sense of control over their time in the short-term, they were unable, just like their fellow patients in conventional haemodialysis, to colonise the future in a way that allowed them to engage in self-actualisation.

For persons undergoing haemodialysis, time is thus in many ways an ambiguous thing. On the one hand, the temporal structure of life with the treatment constitutes a prerequisite for their ability to regain a sense of orientation in the world. On the other, it constitutes a feature of their life that constantly threatens to undermine this ability. While their frequent and regular return to the haemodialysis unit enables them to create a synthesised and situated sick body that allows them to navigate away from disruptive bodily dys-appearances, the intrusion of the treatment and the erraticism of their body into their life make time a potentially disorienting element. This suggests that medical professionals should not too hastily enlist their patients as experts on their own bodies, but rather provide them with the time and support necessary for making repeated attempts at creating and maintaining a life with a sick body.

Swedish summary / Svensk sammanfattning

Vänligen ha tålamod

En kulturfenomenologisk studie
av hemodialys- och njurtransplantationsvård

Den här avhandlingen undersöker de former av person- och patientskap som skapas och förhandlas i hemodialys- och njurtransplantationsvård samt i njursjukas vardagsliv. Ett av avhandlingens grundläggande antaganden är att dessa vårdformer och vardagsliv är djupt sammanflätade med och formade av de kulturella, historiska, ekonomiska och politiska kontexter inom vilka de försiggår. De är därför både bärare och skapare av de normer, värden och intentioner som återfinns i dessa kontexter. Avhandlingens ambition är att utforska på vilka sätt de former av person- och patientskap som skapas och förhandlas i de undersökta vårdpraktikerna och vardagsverkligheterna är kulturellt formade och normativt laddade.

Avhandlingen är tillkommen inom forskningsprojektet *Kroppen som gåva, resurs och vara: organtransplantationer i Östersjöområdet*, som involverade forskare från Södertörns högskola och Lunds universitet och finansierades av Östersjöstiftelsen. Som dess titel indikerar var projektets fokus organtransplantationer. Denna avhandling undersöker dock i minst lika hög grad det andra behandlingsalternativ som erbjuds personer som lider av njursvikt, nämligen dialys, eller närmare bestämt hemodialys. Detta har sin upprinnelse i den tidigare humanistiska och samhällsvetenskapliga forskningens något ensidiga fokus på själva utbytet av organ. En ambition med avhandlingen är att bidra till att bredda detta fokus så att det även inkluderar de njursjukas insjuknande och liv med sjukdomen, deras möte och liv med hemodialys samt deras erfarenheter av att vara transplanterade. Intentionen är att på så sätt bidra till en ökad förståelse inte bara av organtransplantation, utan också av den komplexitet som kroniskt sjuka kastas in i när de möter sjukvården och börjar söka efter sätt att leva med de medicinska behandlingarna och sin förändrade kroppslighet. Studien har därmed ett uttalat patientfokus.

Avhandlingens empiriska material är etnografiskt till sin natur och består av observationer och djupintervjuer med patienter och vårdgivare på fyra hemodialysavdelningar: en i Riga, Lettland, och tre i Stockholm, Sverige. Totalt intervjuades fyrtiotvå personer, varav tjugofem var patienter. När studien undersöker njurtransplantation är det alltså från hemodialyspatienters perspektiv. En ambition har dock varit att inkludera personer med så varierade erfarenheter av de två behandlingsalternativen som möjligt. Bland de medverkande finns därför de som precis har börjat med hemodialys och de som har haft behandlingen i över tjugo år. Vissa av dem väntar på sitt första transplantat, medan andra redan har genomgått en eller flera transplantationer.

Genom sin placering i två nationella kontexter, undersöker avhandlingen också hur historiska, kulturella och politiska processer på transnationella, nationella och lokala nivåer påverkar de vårdpraktiker och vardagsliv som undersöks. Snarare än att från början förutsätta att någon av dessa nivåer är särskilt avgörande utgår studien från de praktiker och berättelser som utgör det empiriska materialet och försöker utröna hur de tre nivåerna samspelar i olika situationer.

Avhandlingens teoretiska ramverk är kulturanalytiskt och fenomenologiskt, och benämns kulturfenomenologiskt. Studien ansluter sig till en förståelse av kulturer som processuella och relationella, som bestående av föreställningar, värden och handlingsmönster som skapas och omskapas i vardagligt handlande. Tyngdpunkten ligger dock på fenomenologiska teorier om kroppslighet och förståelsen av mänsklig existens som fundamentalt förkroppsligad och djupt sammanflätad med den omgivande världen. Tillsammans med det kulturanalytiska perspektivet används detta fenomenologiska perspektiv i avhandlingen som ett sätt att undersöka på vilka sätt personer med njursvikt orienteras och formas, som förkroppsligade personer, av de behandlingsformer de genomgår, de förändringar som sker i deras kroppar och de kulturella kontexter inom vilka detta äger rum. Genom denna analytiska ansats synliggörs också det kontextuellt situerade arbete som de njursjuka ständigt ägnar sig åt för att existentiellt, känslomässigt och praktiskt hantera livet med sjukdomen och behandlingarna, ett arbete som, i sig, omformar deras kroppslighet och omorienterar dem i tillvaron.

Efter avhandlingens två inledande kapitel följer fem kapitel där det empiriska materialet analyseras. Dessa är strukturerade på ett sätt som i stor utsträckning överensstämmer med den kronologi med vilken de flesta som insjuknar med njursvikt möter och lever med sjukdomen och de två behandlingsalternativen. Men till skillnad från denna bok, vilken har ett definitivt slut, visar det sig att personer med njursvikt, när de har erfarit båda behandlingsalternativen, upplever att de befinner sig i ett slags cykliskt tillstånd, där hemodialys och transplantation avlöser varandra.

Kapitel 3 handlar om de medverkandes väg mot patientskapet, om deras insjuknande och möte med diagnosen njursvikt och de två behandlingsalternativen. En majoritet av studiens deltagare diagnosticerades innan de upplevde några sjukdomssymptom. Detta upplevde en del av dem som djupt desorienterande. För andra erbjöd diagnosen och den medföljande prognostiska informationen om när sjukdomen beräknades bryta ut en möjlighet att behålla orienteringen i tillvaron. Dessa variationer lyfts i kapitlet fram som tecken på medicinska diagnosers ambivalens. Eftersom de fästs vid en person som befinner sig i en specifik förkroppsligad situation är deras effekter aldrig på förhand givna. Detsamma visade sig gälla deltagarnas första möte med hemodialysbehandlingen, vilken var den behandlingsform de alla mötte först. Trots att deras vårdgivare var måna om att förbereda dem för detta möte, en ambition som gick i linje med de nya, nyliberalt influerade, idealen kring patientskap som vuxit fram de senaste decennierna, var deltagarnas upplevelser av den första hemodialysbehandlingen väldigt olika och inte sällan negativa. En liknande komplexitet framträdde i de medverkandes första möte med njurtransplantation. Detta var en särskilt omvälvande erfarenhet eftersom de, innan de genomgick behandlingen, tenderade att vara orienterade i linje med den kraftfulla diskurs som omger organtransplantation, inom vilken denna behandlingsform framstår som oproblematiskt livräddande, hälsobringande och normaliserande. I deras förkroppsligade möte med behandlingen blev deltagarna varse om att denna idealiserade bild var förenklad och tillägnade sig därför en mer pragmatisk hållning gentemot den.

Kapitel 4 utforskar och analyserar tre samspelande copingmetoder som deltagarna använder för att, primärt på ett existentiellt och emotionellt plan, hantera sitt sjukdomstillstånd och behov av behandlingarna. I kapitlet blir det tydligt att behovet av dessa copingmetoder först och främst uppstår när deltagarna möter hemodialysbehandlingen för första gången. Det är då de inser vilken inverkan sjukdomen kommer att ha på deras liv. Vad som vidare framgår är att copingmetoderna inte är idiosynkratiska strategier som de njursjuka själva uppfinner utan att de är djupt sammanflätade med normativa orienteringar som återfinns både inom de studerade vårdpraktikerna själva och i de samhälleliga kontexter där de äger rum. Kapitlet visar också att copingmetoderna, trots att de primärt befinner sig på ett existentiellt och emotionellt plan, är djupt sammanflätade med de praktiker deltagarna är involverade i.

Detta blir ännu tydligare i kapitel 5, där hemodialyspraktiken och de former av patientskap som där skapas och upprätthålls undersöks. Kapitlet visar att hemodialysbehandlingens repetitiva natur gör att patienterna efter ett tag förmår vänja sig vid och göra flera aspekter av behandlingen rutinmässiga och vardagliga, till exempel behandlingsenheternas rumslighet, de teknologier som används, de handlingar som utförs och, inte minst, den egna kroppen som ett medicinskt objekt. Detta skeende analyseras fenomenologiskt som en process genom vilken patienterna förmår göra nya handlingar, ting och rumsligheter till oreflekterade aspekter av sin levda kroppslighet och därigenom göra behandlingspraktiken mer hanterbar. Kapitlet belyser särskilt hur denna process låter patient och sköterska mötas som personer och rikta sin uppmärksamhet bort från de handlingar som gör den sjukes kropp till ett medicinskt objekt. En slutsats som dras är därför att den objektifiering av patientens kropp som äger rum inom medicinsk praktik inte alltid hindrar honom eller henne från att framträda som en fullvärdigt förkroppsligad person.

Detta blir särskilt tydligt när den behandlingsform som kallas ”egenvård” undersöks. I denna behandlingsform sköter patienterna behandlingen själva och förmår på så sätt skapa en syntes mellan sin kropp som ett medicinskt objekt och sin kropp som de lever och upplever den, en syntes som i avhandlingen ges benämningen ”en sjuk kropp” [a sick body]. Skapandet av denna syntes lämnar varken patienternas kroppslighet eller behandlingspraktiken oförändrade utan omvandlar dem båda så att nya sätt att förhålla sig till dem uppstår. Analysen av egenvårdspatienternas berättelser visar också att de, genom att sköta behandlingen själva, upplever att de i viss mån lever upp till de nyliberalt influerade normerna kring patientskap som är verksamma inom de studerade vårdpraktikerna. Kapitlet avslutas med en analys av den händelselöshet som karakteriserar större delen av en hemodialysbehandling. Denna händelselöshet visar sig vara svår för patienterna att hantera. Risken är, menar de, att man drabbas av en slags långtråkighet som öppnar upp ett svårhanterligt existentiellt djup, ur vilket ens utsatta och bräckliga situation framträder. Lösningen är att försöka aktivera sig med någonting, vilket inte alltid är möjligt eftersom behandlingen är så mödosam. Lyckas man kan dock dessa aktiviteter och de ting man aktiverar sig med skapa ett slags avgränsad, privat zon inom vilken man kan framträda som person.

Kapitel 6 förflyttar sig ut ur hemodialyspraktiken och in i de njursjukas vardagsliv. Kapitlet visar att skapandet av en sjuk kropp även försiggår här. I livet utanför behandlingsenheten förmår även de som genomgår den vanligaste, den så kallade ”konventionella” formen av hemodialys – i vilken patienterna genomgår behandlingen tre gånger i veckan, fyra timmar åt gången och är beroende av sjuksköterskorna för att starta, övervaka och avsluta den – skapa en sjuk kropp. Detta gör de genom att oreflekterat koppla samman sina vardagshandlingar och sitt mående med den information om deras kropp som ett medicinskt objekt som genereras i behandlingspraktiken. Här blir det tydligt att den sjuka kropp som skapas inte är avgränsad från den njursjukes totala livssituation, utan utgör en central aspekt av denna. Kroppen som ett medicinskt objekt, det egna måendet och de handlingar som vardagen utgörs av framträder därför inte var och en för sig, utan som ett samlat intentionellt objekt som orienterar den njursjuke i specifika riktningar. Kapitlet visar att deltagarna i studien, genom att skapa en sådan situerad, sjuk kropp, i varierande grad, förmår omorientera sina intentioner och arbeta på sin kropp så att de kan undvika smärtsamma och begränsande sjukdomssymptom. Detta visar sig dock i högre grad vara möjligt för de som sköter sin egen behandling, vilka har möjlighet att påverka hur ofta och hur länge de genomgår denna. Men egenvårdens fördelar på denna punkt avtar när fokus flyttas från kroppsliga processer som följer behandlingens rytm till kroppsliga processer som ger sig tillkänna mer sällan eller som ständigt pågår.

Kapitlet identifierar liknande skillnader och likheter mellan personer som genomgår konventionell hemodialys och personer som sköter den själva när det gäller de tidsliga aspekterna av livet med behandlingen. Medan de förra upplever att behandlingens rytm hindrar dem från att ta kontroll över sin egen tid och, i förlängningen, sitt eget liv, upplever de senare att deras förmåga att påverka när och hur länge de genomgår behandlingen ger dem en känsla av frihet och flexibilitet. Att orientera sig mot och planera inför framtiden upplever dock de allra flesta som mer eller mindre omöjligt, eftersom deras kroppsliga tillstånd när som helst kan försämras. Alla studiens deltagare upplever sig också som rumsligt begränsade av behandlingen, och många uttrycker en frustration över att inte kunna resa, en frustration som, tillsammans med irritationen över det förlorade inflytandet över tiden, i kapitlet placeras inom en nyliberal kontext där rörlighet och en orientering mot framtiden är dominerande ideal. Kapitlet visar också hur deltagarnas relation till det egna hemmet förändras när de insjuknar och blir beroende av hemodialys. Hemmet framstår då för många som högst ambivalent, som, å ena sidan, en säker plats relativt fri från sjukdom och medicin, och, å andra sidan, som en riskfylld plats vars rumslighet har förändrats och ständigt riskerar att invaderas av medicinska föremål och praktiker. Kapitlet avslutas med ett avsnitt där skillnaderna mellan de ekonomiska förutsättningar som de svenska respektive de lettiska deltagarna lever under diskuteras. Eftersom majoriteten av deltagarna inte har kunnat fortsätta arbeta efter att de har insjuknat är de tvungna att leva på sjukersättning. I Lettland är denna ersättning dock mycket låg, inte sällan under existensminimum, vilket tvingar vissa ut i jobb, medan andra är hänvisade till hjälp från släkt och vänner. De svenska deltagarna, å andra sidan, beskriver den sjukersättning de erhåller som tillräcklig. Flera av dem skulle dock vilja arbeta deltid för att slippa förlita sig i så stor utsträckning på statlig ersättning och för att känna sig mer aktiva.

I kapitel 7 diskuteras den pragmatiska hållning till transplantationsalternativet som deltagarna tenderar att tillägna sig när de har genomgått behandlingen en första gång. Kapitlet visar att även en positiv transplantationserfarenhet ger upphov till en omorientering i förhållande till behandlingen. Genom de återkommande medicinska kontrollerna och behovet av att ta immunhämmande mediciner blir personer som lever med ett njurtransplantat varse om den ständiga risken för avstötning och organets successivt försämrade funktion, insikter som får dem att inse att transplantation inte är en universellt och oproblematiskt livräddande, hälsobringande och normaliserande behandling. Kapitlet tar även upp två paradoxer som livet med ett njurtransplantat frambringar. I den ena upplevs den transplanterade kroppen som paradoxal eftersom dess överlevnad nu hänger på ett intag av läkemedel som uppfattas som giftiga medan livet med hemodialys gick ut på att avlägsna kroppen från giftiga substanser. I den andra upplevs livet med ett transplantat som paradoxalt eftersom möjligheten att återvända till arbetslivet också för med sig en ökad risk att dra på sig smittosamma infektioner som kan leda till organavstötning. Kapitlet lyfter även fram den smärtsamma ambivalens som framträder för personer som, trots att de lever med vad som enligt medicinska mått skulle betraktas som ett fungerande transplantat, inte upplever en förbättrad hälsa efter behandlingen. Att de mest använda medicinska mätmetoderna inte är kapabla att ta i beaktande de njursjukas upplevelser av organtransplantation blir också tydligt i relation till transplantation med organ från levande givare, som inom den medicinska kontexten ses som det bästa behandlingsalternativet, men som de njursjuka många gånger ser som ett omöjligt alternativ på grund av komplexa relationella och sociokulturella omständigheter.

Kapitlet diskuterar avslutningsvis de olika sätt på vilka deltagarnas pragmatiska hållning till transplantationsalternativet manifesterar sig. Denna hållning visar sig både som en förmåga och vilja till att jämföra de två behandlingsalternativen, med hänsyn till deras kontingenta och komplexa natur, och som en medvetenhet om de risker och den ovisshet som utbytet av organ är förenat med. Men en pragmatisk hållning präglar också deltagarnas inställning till att vänta på ett nytt organ. Snarare än att vänta aktivt och otåligt, skapar deras tidigare erfarenheter av njurtransplantation och deras medvetenhet om den ovisshet som präglar denna behandlingsform en slags passiv väntan som primärt är oreflekterad och som bara då och då aktivt tematiseras.

Det avslutande, åttonde kapitlet sammanfattar och diskuterar studiens resultat. En slutsats som dras är att kroniskt sjukas förkroppsligade möten med medicinska diagnoser och behandlingar många gånger frambringar en komplexitet som gör dem oförmögna att leva upp till de normer och ideal som existerar kring patientskapet och vissa behandlingsformer. En annan slutsats är att idén om patienten som en expert på sin egen kropp och sjukdom, en idé som når en allt större spridning, behöver modifieras. Avhandlingen visar nämligen att en sådan expertkunskap om den egna kroppen som sjuk inte existerar från början utan måste tillägnas, en tillägnelseprocess som lika mycket är en skapelseprocess och som innefattar såväl kroppen själv som medicinska teknologier och praktiker. Resultatet är det som i avhandlingen benämns ”en sjuk kropp”, vilken alltid är föremål för förändring och aldrig kan separeras från den specifika situation i vilken den sjuke befinner sig i. I denna process är tid en viktig aspekt. Det är genom sin repetitiva natur som hemodialysbehandlingen förser de njursjuka med de erfarenhetsmässiga och praktiska verktyg de behöver för att skapa en sjuk kropp. Avhandlingen visar också att standardiseringen av hemodialysbehandlingens repetitiva temporalitet ger upphov till ett slags transnationellt ”hemodialysliv”, i vilket de njursjuka konfronteras med liknande utmaningar, gör liknande erfarenheter och tillägnar sig likartade handlingsmönster. En av de största utmaningarna de möter är dock att handskas med själva denna temporalitet, att leva med en behandling som fragmenterar deras liv och gör dem oförmögna att ta kontroll över sin egen tid. Medan det efter ett tag blir möjligt att arbeta med och omforma sin kroppslighet, blir hemodialysens tidsliga rytm inte med tiden lättare att leva med.

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Appendix 1

Jautājums par piedalīšanos intervijā par dialīzi un orgānu transplantāciju

Labdien!
Mani sauc Martins Gunarsons, un es rakstu Jums īpašajā jautājumā. Es esmu doktorants etnoloģijā Sēdertērnas Augstskolā un Lundas Universitātē Zviedrijā, un piedalos pētniecības projektā ”Ķermenis kā dāvana, resurss un prece - orgānu transplantācija Baltijas jūras valstīs”. Pētniecības projekta vadītājs ir Fredriks Svenaeuss, Sēdertērnas augstskolas profesors.

Ar šīs vēstules palīdzību gribu jautāt Jums par Jūsu vēlmi sniegt interviju. Taču pirms Jūs izlemsiet piedalīties vai ne, Jūs noteikti interesē uzzināt, kādēļ intervija notiek un ko nozīmē Jūsu līdzdalība. Tādēļ izlasiet, lūdzu, sekojošo informāciju.

Kāds ir projekta mērķis?

Kā etnologu medicīnas jomā, mani interesē kulturālie procesi, kas rada uzskatus par ķermeni, veselību un slimībām, dzīvību un nāvi. Pētniecības projekta galvenais mērķis ir izpētīt, kā cilvēki ar hronisko nieru nepietiekamību dzīvo un ko domā par dialīzi un orgānu transplantāciju. Tāpat šī projekta ietvaros svarīgi izpētīt pacientu un veselības aprūpes un tās pārstāvju mijiedarbības ietekmi uz situācijas izpratni no dalībnieku puses.

Kādā veidā notiks intervija un ko no manis sagaida?

Intervija ilgst vienu līdz divām stundām. Tā kā es nerunāju latviski, man palīdzēs tulks, kas ir kvalificēts veikt etnogrāfiskās intervijas ar striktu konfidencialitātes ievērošanu. Intervijā es uzdošu vispārīgus jautājumus par Jūsu ikdienu un par Jūsu izjūtām un domām par dialīzes norisi un orgānu transplantāciju un it sevišķi par orgānu transplantāciju.

Intervija tiks ierakstīta atskaņotājā, lai pēc tam to pārveidotu par rakstīto tekstu un pārtulkotu uz angļu valodu. Audioieraksts dod pētniekam iespēju koncentrēties uz interviju, nevis piezīmju pierakstīšanu, kā arī atvieglo sekojošo intervijas apstrādi.

Kas notiek ar intervijas rezultātu?

Jūsu intervijas laikā izteiktās domas būs svarīga pētniecības projekta materiālu sastāvdaļa. Materiāli tiks izmantoti tikai anonīmā formā un Jūsu personīgie dati paliks konfidenciāli. Tas nozīmē, ka izteiktu viedokli nevarēs saistīt ar kādu konkrētu personu. Intervijas ieraksts tiks apstrādāts un uzglabāts saskaņā ar Zviedrijas likumu prasībām par informācijas aizsardzību.

Ja es izvēlos piedalīties, ko no manis sagaida tālāk?

Šīs informācijas lapas beigās atrodas anketa par piekrišanu, ko lūdzu Jums uzmanīgi izlasīt, un, ja Jūs esat ieinteresēts/ -a, parakstīties. Tā ir rakstiska vienošanās par dalību, kas jāņem līdzi, ierodoties uz interviju. Vietu un laiku intervijai izvēlāties Jūs.

Informētas piekrišanas lapa

Intervija par dialīzi un orgānu transplantāciju

Es piekrītu sniegt interviju par augstāk minēto tēmu, kā aprakstīts projekta informācijas lapā (pievienota šai anketai). Esmu informēts/-a par to, ka es piedalos pētniecības projektā un kādā veidā notiks intervija, kā arī par to, kā interviju dokumentēs un uzglabās.

Ja es kā dalībnieks vēlos pārtraukt interviju, man ir tiesības to darīt jebkurā brīdī, nepaskaidrojot iemeslu. Tas pētniecības materiāls, kas attiecas uz mani, tiks iznīcināts un netiks izmantots projektā.

Es piekrītu šīs intervijas audioierakstam, ka arī šī ieraksta transkripcijai un tulkošanai. Intervijas analīze un interpretācija tiks veikta anonīmā formā, kas nozīmē, ka izteikto viedokli nevarēs saistīt ar konkrētu personu. Es apzinos, ka daži no maniem citātiem anonīmā formā var tikt izmantoti zinātniskos rakstos un publiski pieejamās publikācijās.

Pētnieki apņemas nodrošināt intervijas dalībnieku personību konfidencialitāti. Kad projekts būs pabeigts, intervijas materiāli tiks apstrādāti un saglabāti saskaņā ar Zviedrijas likumu prasībām par informācijas aizsardzību.

Vieta un datums

Paraksts

ВОПРОС ОБ УЧАСТИИ В ИНТЕРВЬЮ О ДИАЛИЗЕ И ТРАНСПЛАНТАЦИИ ОРГАНОВ

Добрый день!

Меня зовут Мартин Гунарсон, и я пишу Вам в связи с особым вопросом. Я являюсь докторантом в области этнологии в Университете Седертерна и Лундского Университета в Швеции и участвую в исследовательском проекте ”Тело как дар, ресурс и товар: трансплантация органов в государствах Балтийского региона”. Руководителем проекта является Фредерик Свенаеус, профессор Седертернского ВУЗа.

С помощью этого письма хочу спросить Вас о желании дать интервью. Но перед тем, как Вы решите участвовать или нет, Вы наверняка хотите узнать, почему проходят интервью и каково значение Вашего участия. Поэтому прочтите, пожалуйста, следующую информацию.

Какова цель проекта?

Как этнолога в области медицины меня интересуют культурные процессы, связанные с тем, как создаются различные взгляды на тело, здоровье и болезни, жизнь и смерть. Главная цель исследовательского проекта изучить, как живут люди с хронической почечной недостаточночтью и что они думают о диализе и трансплантации органов. Так же важным для проекта является исследование влияния взаимодействия между пациетами и системой здравоохранения, ее представителями на восприятие ситуации ее участниками.

Как будет проходить интервью и что от меня ожидается?

Интервью занимает от одного до двух часов. Так как я не говорю по-русски, мне будет помогать переводчик, квалифицированный к проведению этнографические интервью с соблюдением полной конфиденциальности. В течение интервью я задам общие вопросы о Ваших буднях и о Ваших чувствах и мыслях о ходе диализа и трансплантации органов, в особенности о трансплантации органов.

Интервью будет записываться на диктафон, чтобы потом его можно было перевести в письменный текст, а затем и на английский язык. Аудиозапись дает возможность исследователю концентрироваться на интервью, а не на записывании заметок, а так же облегчает последующую обработку.

Что происходит с данными интервью?

Ваши мысли, высказанные в течение интервью, бутут составлять важную часть материалов исследовательского проекта. Материалы будут использоваться только в анонимной форме и со строгим соблюдением конфиденциальности Ваших личных данных. Это значит, что высказанное мнение нельзя будет связать с какой-либо конкретной персоной. Запись интервью будет обработана и сохранена в согласии с требованиями законов об охране информации в Швеции.

Что от меня ожидается, если я хочу участвовать в интервью?

В конце этого информационного листа находится анкета о согласии, которое прошу Вас внимательно прочитать, и если вы заинтересованы, подпишитесь, пожалуйста. Это писменное соглашение об участии, которое нужно взять с собой, приходя на интервью. Место и время для интервью выбираете Вы.

Форма информированного согласия

Интервью о диализе и трансплантации органов

Я соглашаюсь дать интервью на вышеупомянутую тему согласно с тем, как описано в информационном тексте о проекте (прилагается к этой анкете). Я информирован/ -а о том, что я участвую в исследовательском проекте, и том, какова цель интервью и как оно будет проходить, документироваться и храниться.

Если я, как участник, хочу прервать интервью, у меня есть право сделать это в любой момент, не объясняя причину. Тот исследовательский материал, который относится ко мне, будет уничтожен и не будет использоваться в проекте.

Я соглашаюсь на аудиозапись интервью, а также на его транскрипцию и перевод. Анализ интервью и его интерпретация будут проходить в анонимной форме, что означает невозможность связать высказанное мнение с какой-либо конкретной персоной. Я осознаю, что некоторые из моих цитат в анонимной форме могут быть использованы в научных статьях и общественно доступных публикациях.

Личность участников интервью будет сохранена исследователями в стогой конфиденциальности. Когда проект будет завершен, материалы интервью будут обработаны и сохранены в согласии с требованиями законов об охране информации в Швеции.

Место и дата

Подпись

Förfrågan om deltagande i en intervjustudie om dialys och njurtransplantation

2010-09-14

Hej!

Jag heter Martin Gunnarson och skriver till dig eftersom jag genomför intervjuer med personer med kronisk njursvikt. Det här brevet är en förfrågan om du skulle kunna tänka dig att medverka i denna intervjustudie.

Jag är doktorand i etnologi på Södertörns högskola och Lunds universitet och medverkar med ett delprojekt i forskningsprojektet ”Kroppen som gåva, resurs och vara, organtransplantationer i östersjöområdet”. Mitt delprojekt heter ”Relationen mellan person, kropp och medicinsk miljö på fyra dialysenheter, en i Riga och tre i Stockholm”.

Som etnolog inom det medicinska fältet är jag intresserad av hur olika uppfattningar om sådant som kropp, hälsa och sjukdom skapas. I delprojektet, som handlar om hur människor med njursvikt lever med och förhåller sig till dialys och transplantation, gör jag både observationer på dialyskliniker och intervjuer med personer med anknytning till dessa.

Hittills har fältarbetet varit inriktat på observationer. Jag har följt med i verksamheten med ambitionen att få en förståelse för olika slags rutiner och förhållningssätt vid dialysbehandling. Men nu har jag kommit till den fas i projektet då jag ska genomföra ett antal intervjuer.

Intervjun tar mellan en och två timmar. I intervjun kommer jag att ställa frågor kring din vardag i allmänhet och kring dina upplevelser av och tankar kring dialysbehandling och transplantation i synnerhet. På så sätt innebär samtalet också en möjlighet för dig att delge dina erfarenheter och uppfattningar av ditt möte med den svenska sjukvården.

Intervjun kommer att spelas in på band för att därefter skrivas ut. Tid och plats för samtalet bestämmer du själv. Intervjun utförs under tystnadsplikt.

Det färdiga forskningsmaterialet består alltså av ett antal bandinspelade och utskrivna intervjuer. Detta material kommer endast jag som forskare att ha tillgång till under projekttiden. Materialet kommer att användas till vetenskapliga artiklar och publikationer. Det kommer då att vara anonymiserat och avidentifierat så att inga individer ska kunna kännas igen. När projektet är avslutat överlämnas intervjumaterialet till Folklivsarkivet vid Lunds universitet, där det kommer att vara belagt med sekretess enligt gängse bestämmelser.

Deltagande i forskningsprojektet är frivilligt och du har rätt att när som helst avbryta ditt deltagande, utan särskild förklaring. Det forskningsmaterial som gäller dig kommer då att förstöras och inte användas i projektet. Ditt val att avbryta deltagandet i projektet kommer inte att påverka din fortsatta behandling.

Vänligen
Martin Gunnarson

Vid förfrågningar ring 08-608 48 01 eller maila martin.gunnarson@sh.se

TALONG FÖR INFORMERAT SAMTYCKE

Härmed samtycker jag till att låta mig intervjuas för studien ”Relationen mellan kropp, person och medicinsk miljö på fyra dialysenheter, en i Riga och tre i Stockholm”. Jag har tagit del av informationen kring projektet och känner till de förutsättningar som gäller för min medverkan.

Namn:

Telefonnummer:

Ort och datum:

Signatur:

Om du bestämmer dig för att medverka hör jag av mig till dig för att bestämma tid och plats för intervju så snart jag har mottagit talongen.

Vid förfrågningar, kontakta Martin Gunnarson
08-6084801, martin.gunnarson@sh.se

Talongen sänds till:

Martin Gunnarson, doktorand
Centrum för praktisk kunskap
Institutionen för kultur och kommunikation
Södertörns högskola
141 89 Huddinge

Förfrågan om deltagande i en observationsstudie om dialys och njurtransplantation

2010-09-14

Hej!

Jag heter Martin Gunnarson och skriver till dig eftersom jag genomför observationer på dialysmottagningar i Stockholm. Det här brevet är en förfrågan om du skulle kunna tänka dig att medverka i denna observationsstudie.

Jag är doktorand i etnologi på Södertörns högskola och Lunds universitet och medverkar med ett delprojekt i forskningsprojektet ”Kroppen som gåva, resurs och vara, organtransplantationer i östersjöområdet”. Mitt delprojekt heter ”Relationen mellan person, kropp och medicinsk miljö på två dialyskliniker, en i Riga och en i Stockholm”.

Som etnolog inom det medicinska fältet är jag intresserad av hur olika uppfattningar om sådant som kropp, hälsa och sjukdom skapas. Delprojektet undersöker hur människor med njursvikt lever med och förhåller sig till dialys och njurtransplantation. Viktig i studien är därför att få en förståelse för den miljö i vilken dialysbehandlingen äger rum.

Denna miljö studerar jag genom en metod som, inom etnologin, kallas deltagande observation. Deltagande observation går ut på att man som forskare närvarar med sin egen person i de olika situationer man studerar. I projektet innebär detta att jag, under några dagar, följer vårdpersonal (sköterskor och läkare) i deras arbete på dialysavdelningen. Detta betyder att jag, tillsammans med en sköterska eller läkare, kommer att befinna mig på mottagningen under tiden för din behandling.

De deltagande observationerna skrivs sedan ner i en så kallad fältdagbok. Detta material kommer endast jag som forskare att ha tillgång till. Materialet kommer att användas till vetenskapliga artiklar och publikationer. Det kommer då att vara anonymiserat och avidentifierat så att inga individer ska kunna kännas igen.

Deltagande i forskningsprojektet är frivilligt och du har när som helst rätt att avbryta ditt deltagande, utan särskild förklaring. Det forskningsmaterial som gäller dig kommer då att förstöras och inte användas i projektet. Ditt val att avbryta deltagandet i projektet kommer inte att påverka din fortsatta behandling.

Vänligen

Martin Gunnarson

Vid förfrågningar ring 08-608 48 01 eller maila martin.gunnarson@sh.se

TALONG FÖR INFORMERAT SAMTYCKE

Härmed samtycker jag till att delta i observationsstudien ”Relationen mellan kropp, person och medicinsk miljö på två dialyskliniker, en i Riga och en i Stockholm”. Jag har tagit del av informationen kring projektet och känner till de förutsättningar som gäller för min medverkan.

Namn:

Telefonnummer:

Ort och datum:

Signatur:

Vid förfrågningar, kontakta Martin Gunnarson
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Appendix 2

APPENDIX 2

Overview of interviewed patients

Riga

Ivan

Ivan is 22 years old and lives with his parents. He underwent haemodialysis for the first time in 2007 and is yet to be admitted to the waiting list for transplantation.

Pyotr

Pyotr is 41 years old and lives with his wife and their two children. He has undergone haemodialysis for four months and has just been admitted to the waiting list for transplantation.

Liouba

Liouba is 44 years old and lives by herself in an apartment in Riga. Her son, who is 25 years old, lives in Belarus. She fell ill in 2006 and was admitted to the waiting list for transplantation during the fall of 2009.

Dmitry

Dmitry is 38 years old and lives with his wife and their 13-year-old son. He underwent haemodialysis for the first time in 1996. Since then he has been transplanted twice.

Valda

Valda is 53 years old. She lives with her husband, with whom she has four sons. She underwent haemodialysis for the first time in 1995. Since then she has been transplanted on two occasions.

Lidija

Lidija is 43 years old and lives with her husband and their daughter. She underwent haemodialysis for the first time in 2000. Since then she has been transplanted twice.

Nadya

Nadya is 29 years old and spends half of her time with her parents in Dobele and half of her time with her boyfriend in Riga. She underwent haemodialysis for the first time in 1994. Since then she has been transplanted on two occasions.

Yevgeniy

Yevgeniy is 55 years old. He lives with his wife, with whom he has two children. He underwent haemodialysis for the first time in 2005 and has been transplanted once.

Filips

Filips is 40 years old. He lives with his mother and his two siblings. He underwent haemodialysis for the first time in 1998. Since then he has been transplanted on three occasions.

Stanislav

Stanislav is 32 years old and lives alone in Olaine, a small town just south of Riga. He underwent haemodialysis for the first time in 2005 and has turned down the doctors' offers to admit him to the waiting list for transplantation.

Andrejs

Andrejs is 34 years old and lives with his wife and their three children. He underwent haemodialysis for the first time in September 2009 and is yet to be admitted to the waiting list for transplantation.

Egils

Egils is 48 years old and lives with his wife and their children in central Riga. He underwent haemodialysis for the first time in 2002 and has been transplanted once.

Indra

Indra is 69 years old and lives with her husband. She underwent haemodialysis for the first time in 2008 and has been deemed ineligible for transplantation.

Boris

Boris is 59 years old and lives with his mother. He has two grown children from an earlier marriage. He underwent haemodialysis for the first time in February 2009 and has been deemed ineligible for transplantation.

Daina

Daina is 65 years old and lives by herself in Riga. She underwent haemodialysis for the first time in 2008 and is yet to be admitted to the waiting list for transplantation.

APPENDIX 2

Stockholm

Veronica

Veronica is 55 years old and lives with her husband and their 13-year-old daughter. She underwent haemodialysis for the first time in 2001 and has been transplanted once.

Sven

Sven is 67 years old and lives with his wife, with whom he has two children. He underwent haemodialysis for the first time in the beginning of the 1990s. Since then he has been transplanted on one occasion.

Marianne

Marianne is 56 years old and lives with her husband, with whom she has a grown daughter. She underwent haemodialysis for the first time in 1987 and has been transplanted on two occasions since then.

Rune

Rune is 73 years old and lives with his wife, with whom he has two children. He underwent haemodialysis for the first time in 1980 and has been transplanted twice.

Carlos

Carlos is 50 years old and lives by himself in Stockholm. He underwent haemodialysis for the first time in 1997 and has been transplanted on one occasion since then.

Eva

Eva is 59 years old and lives with her husband. She underwent haemodialysis for the first time in 2008 and is yet to be admitted to the waiting list for transplantation.

Tomas

Tomas is 64 years old and lives by himself. He underwent haemodialysis for the first time in 2008 and is yet to be admitted to the waiting list for transplantation.

Hans

Hans is 47 years old and lives with his wife. He underwent haemodialysis for the first time in 2007 and is waiting for his first transplant.

Camilla

Camilla is 30 years old and lives with her sister. She underwent haemodialysis for the first time in 2000 and has been transplanted once.

Bengt

Bengt is 62 years old and lives with his wife. He underwent haemodialysis for the first time in 2006 and has been deemed ineligible for transplantation.

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Please Be Patient examines the practice of haemodialysis and kidney transplantation, the two medical therapies available for persons with kidney failure, from a phenomenological perspective. A basic assumption being made is that contemporary biomedicine is deeply embedded in the cultural, historical, economic, and political circumstances provided by the particular local, national, and transnational contexts in which it is practiced. The aim of the investigation is twofold. On the one hand, the aim is to examine the forms of person- and patienthood enacted and negotiated in haemodialysis and kidney transplantation care and in the daily lives of persons with kidney failure. On the other hand, the aim is to investigate the ways in which the enacted and negotiated forms of person- and patienthood are culturally embedded and normatively charged.

In order to examine and investigate this twofold aim, an empirical material has been gathered that comprises observations and in-depth interviews with patients and caregivers at four haemodialysis units, one in Riga, Latvia, and three in Stockholm, Sweden. The theoretical approach and methodology of the study is cultural and phenomenological in character, drawing on an ethnological and anthropological understanding of culture as processual and relational, and on a phenomenological understanding of personhood as embodied and intertwined with the surrounding world.

Martin Gunnarson is an ethnologist at the Department of Arts and Cultural Sciences, Lund University, and at the Centre for Studies in Practical Knowledge, Södertörn University. *Please Be Patient* is his doctoral thesis.

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