Modern Genes : Body, Rationality and Ambivalence

Hagen, Niclas

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Niclas Hagen

LUND
UNIVERSITY

To Ulla-Brith, Oskar and Else-Marie

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Berlin July 28, 2013

Niclas

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Preface

This important relationship, and all that is connected with it, is expressed within the science of heredity through the theorem, which states that the phenotypic character does not always reveal the character of the genotype. (Johannsen, 1917: 123. My translation).

I did not know my biological father. My memories of him are few, restricted to a few fragments of childhood memories that I think originate from a time immediately before our continuous contact ceased for various reasons. I did talk with him over the phone a couple of times during my adolescence, so eventually I could connect these childhood memories to a voice but I never took the chance to meet him in person. My father died in 2008. A sudden phone call from his brother passing on the news of his death unexpectedly put me in a context wherein the nature of my genealogy, hitherto restricted to the families of my mother and my stepfather, became biological. In one important way, the contact between my father and myself never ceased to exist, as 50 % of my genetic material consists of genes that I have inherited from him. I had a theoretical awareness if this relationship through my undergraduate studies in molecular biology and genetics, but it was not until I met my half-brother and the rest of the family at my father's funeral that this theoretical knowledge manifested itself within my daily existence.

It was almost a surrealistic experience when those who knew him spotted the resemblance between us. On one occasion, at a family celebration that took place in 2010, one of his best friends told me that his immediate response, when I walked through the room, was that it was my father and not I that he saw passing by. I say surrealistic because despite the fact that science has thoroughly convinced me of the existence of genetic material

within my body, this is indeed a knowledge that is both abstract and very much dislocated from the way I perceive and experience my body within my everyday life. These remarks about my resemblance with my father did not invoke a substantial change in my identity. I still regard and think about myself very much in the same way as I did before; nevertheless, these remarks did something with me. My father's death "exposed" my genetic material for me, an "exposure" that transformed my theoretical understanding of genetics into an embodied experience. And it did not take long until this embodied experience stirred up thoughts and emotions about the nature of these genes. It was not about their chemical composition and their functions deep inside my body, but about whether these genes in fact contained something that could be dangerous for me. These thoughts eventually caused me to pick up the phone and call my half-brother to ask him about the cause of death for a number of my paternal relatives. It was a phone call driven by this "exposure" of parts of my body, which I did not have any direct experience of through my senses. Despite all my rational and theoretical knowledge about genetics, I was worried about what might lie buried deep inside my body.

I never did anything to find out whether my genes did contain any variations that could affect my health. The only action that I took was this phone-call to my half-brother. Any worries that I had regarding my genes, soon disappeared in the midst of my daily life, lived as it is through those parts of my body that I can see and experience through my senses. I do not know how I would have reacted if my genes posed a threat towards my health. I choose to back away from my genome, and leave it alone. At least for the time being…

1. Introduction

Thomas is going to pick me up at his local train station. I am going to interview him and his wife Paula about their daily life with Huntington´s disease, which is a genetic disease that primarily affects the brain. Currently, no medical intervention exists that cures or slows the progression of the disease. The disease is caused by one mutated gene, which has what is called a 100% penetrance. This means that if you carry the mutation within your genome, you will inevitably become afflicted with Huntington's disease sometime in the future. There is a 50% risk that a child of an affected parent inherits the mutation. It is a rare disease; in Sweden, there are about 1000 individuals who are diagnosed with the disease. The disease exhibits a range of psychiatric, neurological and cognitive symptoms, such as depression, involuntary movements and dementia. Typically, it commences in mid life with neurological symptoms in the form of involuntary movements. However, in many cases, various forms of psychiatric symptoms might precede these neurological symptoms, but the formal diagnosis is set when the affected individual has clear neurological signs and symptoms. In general, the affected individual dies 10-16 years after the first appearance of the neurological symptoms. Since 1993, a predictive genetic test is available; those who are at risk can establish whether they carry the mutation within their genome (Petersén, 2001: 15-16; Quarrell, 2008).

Paula suffers from Huntington's disease. She and Thomas live about one hour away by train from me. After a few minutes waiting at the station, Thomas appears by car and we arrive at his and Paula´s semi-detached house after a short stop in order to get some groceries. When I step inside Thomas and Paula's house, Paula greets me as she slowly walks towards me from an adjacent room to the hallway. When Paula approaches me, I immediately see that the disease has struck her body because Paula has reached that phase of the disease when clear and visible symptoms are present. She has some difficulty with walking; her movements are quite rigid, a sort of stiffness that seems to turn walking and moving around into quite an effort for her. This visible presence of clear signs and symptoms of the disease is something quite different from my meeting with Patricia,

whom I met sometime before my interview with Thomas and Paula. Patricia is in her thirties and she found out that she were at risk of inheriting the mutated gene that causes Huntington's disease in conjunction with her father's diagnosis. She decided to go through with taking a predictive genetic test in order to find out if her genome contained the mutated gene that causes the disease. The predictive test revealed that the mutated gene is part of her genome. Due to the 100% penetrance of the mutation, this means that she inevitably will be afflicted with Huntington's disease sometime in the future. As far as I can see, when Patricia and I have an initial meeting over some coffee, there are no visible signs of the mutated gene. For all those (and me!) who saw us carrying our trays over to the table, we must have looked like two individuals in the midst of life who were just out for a chat and some coffee. The brute reality of this meeting, the fact that Patricia's genome contains a genetic mutation that eventually will make her fatally ill, seemed rather abstract and even elusive as we sat down at our table. Yet, the sheer complexity of this situation becomes clear for me when I use the terms gene-carrier or pre-symptomatic patient, in order to describe the situation that Patricia faces as a consequence of the predictive genetic test. Patricia reacts when I use these terms because in her opinion, these terms imply a non-presence of the disease; something "yet to happen" in her body and in her life. However, during our interview that took place at a later occasion, Patricia talked about those signs and symptoms that she in fact could perceive. To some extent, this "yet to happen" has already happened despite there were no visible signs of Huntington's disease.

Due to the visibility of Paula's neurological symptoms, this sort of ambiguity was not present when I sat down with Paula and Thomas. Yet, both Thomas and Paula mentioned experiences in their daily life that, although of a different kind, bear some resemblance to that kind of ambivalence that Patricia faced as a "pre-symptomatic" patient. For Paula and Thomas, these ambiguous and ambivalent experiences arose as Paula's health got worse and they, Thomas being Paula's carer, needed help and assistance from the Swedish welfare system. In their contacts with the welfare system, their everyday life with Huntington's disease was evaluated by the welfare system, as a way to decide whether Paula was ill enough to obtain assistance from the state. As in the case with Patricia above, Paula and Thomas' situation could also be described in terms of ambiguity or ambivalence as to whether Paula is deemed ill enough to obtain assistance. Whether or not the daily life of my participants revolved around genes as an invisible and highly abstract part of our bodies, or around the tensions with

the Swedish welfare state, the ultimate matter at stake seemed to concern the status of the participants' everyday experiences of Huntington's disease.

As my research proceeded, it became clear to me that the experiences I encountered in the interviews that I conducted with a number of individuals affected by Huntington's disease were not the only representations of this disease. Instead, these experiences were in fact, in various ways, challenged by representations made by others. These other representations were those offered by genetic science, which provided representations of our body that depart from the way we ordinarily experience and perceive our bodies in daily life. They were also the legal representations used by the welfare system in order to evaluate the everyday situation of the participants. The presence of these two institutions, science and the welfare society, led me to the notion of modernity, since these two institutions can be seen as two very prominent examples of modernity. In my view, these challenges have their origin in cultural patterns that are fundamental to modernity. Furthermore, and maybe more importantly, it was in relation to the status of everyday experience that various zones of conflict, negotiations but also practices that offered forms of cultural and social change could be discerned in my ethnographic material. In order then to explain, not only why those challenges described above arise, but also to increase our understanding of the way genetic knowledge interacts with our culture and our society, these patterns of modernity need to be investigated. This will be achieved only by making the connection between the wider socio-cultural context of modernity and the issues that the ethnographic material revolves around. This broader form of cultural analysis is needed to obtain a deeper knowledge about the connection between these fundamental aspects of modernity and the status of the participants' everyday experiences of Huntington's disease.

In the next chapter, the aims and research questions of this thesis will be made explicate in relation to the general background given in this introduction.

2. Aims and research questions

The main objective of this thesis is to investigate the linkage between everyday life with a genetic disease and intrinsic patterns of modernity. The objective to investigate this linkage becomes especially important as the link between everyday life and modernity gave rise various zones of conflict and practices that offered forms of cultural and social change could be discerned in my ethnographic material. By investigating the link between everyday experiences with general cultural patterns of modernity, the thesis does then provide a deeper knowledge upon the interactions between genetic science, culture and society.

As to the specific research questions that I intend to answer, I have chosen four separate questions; step-by-step, these address different parts of the overall aim presented above. My first research question consequently asks:

- What kind of everyday experiences of Huntington's disease could be discerned in my ethnographic material?

These experiences that take place on the level of everyday life are challenged by representations made by other parties than the affected individuals. In this case, what do I mean by challenge? And how can an everyday experience be challenged? These questions obviously need to be addressed, and I intend to do so through my second research question.

- In what way are these everyday experiences challenged?

Next, the issue of modernity and its connection with the level of everyday life and experience of Huntington's disease will be analysed through the following question.

- How can we understand these challenges as an aspect of modernity?

As I also stated above, my view is that the issues in focus in this thesis attain an importance that reaches beyond the immediate context of Huntington's disease. In order to make this argument more clear and to link

this thesis to a wider context of cultural and social aspects of genetics, I end with asking:

- What are the general implications of these cultural patterns within modernity in relation to the interaction between genetics, culture and society?

This thesis is a compilation thesis that contains four individual articles each addressing the everyday experience of Huntington's disease from different angles, with different research questions and theoretical presumptions. The main function of the introductory part (kappan) is to position the four individual articles as part of a general scientific problem. A further purpose is to investigate this general issue on the basis of the individual articles. The introductory part of the thesis also serves as a way to explore the methodological framework that is used in the individual articles. The four articles of this thesis concern different aspects of everyday experience of Huntington's disease. The ethnographic material of each article was obtained with the same method, largely through semi-structured ethnographic interviews. As a writer of a compilation thesis, you always face the risk of repeating aspects and issues that are already present in other parts of the thesis. Discussions about methodology might for example be repeated in each of the four articles, since such a discussion is mandatory and necessary in order to get the article published. In relation to this introductory part of the thesis, I have tried to avoid reiterating myself too much in relation to what is included in the articles. Certain aspects are however both impossible and undesirable to leave out, even though the reader might find the same kind of discussion in the included articles. Here, I am mainly thinking about such aspects that concern methodology and general features of Huntington's disease.

This is a thesis that has its disciplinary base within ethnology. Nevertheless, it is written within an interdisciplinary research context where researchers from a number of disciplines (medicine, cultural sciences, technology, and the caring sciences) collaborate around research upon Huntington's and Parkinson's disease. This interdisciplinary research environment is called the Basal Ganglia Disorders Linnaeus Consortium (Bagadilico), conducting interdisciplinary research on Parkinson's and Huntington's disease. The consortium is based in Lund, and has about 120 affiliated researchers, students and technicians from Lund University or Lund University Hospital (http://www.med.lu.se/bagadilico/about_us). This circumstance affects my choice of format (compilation of articles instead of the more traditional monograph) but in general also my point of departure for this thesis. There is no shortage of research upon how affected individuals experience

Huntington's disease. Yet, much of this research has been conducted within the caring sciences with a focus upon the micro-level of the lives of the affected individuals. This means that much of the research conducted upon how individuals experience Huntington's disease does not contain a broader cultural analysis that investigates the linkage between these experiences and more general cultural patterns within the Western society.

I will now move on to the disposition of the thesis.

3. Disposition of the thesis

The disposition of the thesis will be as follows:

In the next chapter, chapter four, I will describe Huntington's disease, which is the disease the thesis will be based upon. I will discuss some of the history of the disease, how it can be understood as a late onset disorder and the genetics behind the disease. Its function as a form of model disease in both the medical and the cultural sciences will also be investigated. I will end the chapter with a section on the engagement of patients in medical research on the disease.

In chapter five, I will give an overview of previous research. I will begin with research on Huntington's disease; this will mainly be oriented towards research performed within the caring sciences, concerning how affected individuals experience the disease. Next, I will turn to ethnology, to ethnological research dealing with topics that are relevant for this thesis. Here, I will present previous ethnological research taking an interest in various perspectives of modernity and the modern society, but also ethnological research that investigates cultural aspects of health and medicine. In addition to this, there is a vast amount of research focusing specifically on the scientific development within genetics and biomedicine. After illuminating this research I will move on to specify the contribution of this thesis to the research that I have presented in this chapter.

I will discuss the theoretical framework of the thesis in chapter six. This framework will be based upon the work of the German social theorist Jürgen Habermas on modernity. Of particular interest is his theory of communicative action in which he makes a distinction between lifeworld and system as two different societal spheres within the modern society (Habermas, 1984, 1987). However, in order to achieve the aims of the thesis, I intend to complement Habermas' theory with additional perspectives. These additional perspectives will be the American physician and philosopher Drew Leder's phenomenological perspective of the body, and its absence in everyday life (Leder, 1990). I will also supplement the overall perspective of Habermas with perspectives that I take from philosophy and history of science. These perspectives will come from the

German historian of science, Hans-Jörg Rheinberger, who describes the production of knowledge in terms of experimental systems (Rheinberger, 1997, 2004). Moreover, this aspect of science and the production of scientific knowledge will be combined with arguments made by the French philosopher Gaston Bachelard, who suggests that the production of scientific knowledge contains epistemological obstacles that have to be transgressed in order for science to accomplish scientific knowledge (Bachelard, 2002). In my analysis I will also use post-colonialist theoretician Homi. K. Bhabha' s "Third space" concept as I make an argument for a more gradual differentiation between lifeworld and system instead of the sharp and dichotomous relationship between lifeworld and system that are given through Habermas' theory (Bhabha, 1994).

Chapter seven contains a discussion on methods and material. In the methods section I will discuss various aspects of my fieldwork, including the recruitment of the participants, the conduction of the interviews, transcribing and analysis of the interviews, as well as various ethical considerations in conjunction to my fieldwork. Next, I will discuss and problematize the material of the thesis. This material consists of so called illness narratives, and in this section I will discuss some major aspects of these illness narratives, including epistemological aspects. This discussion will lead on to a reflection upon the limitations of the thesis that will end the chapter

The individual four articles that are included in the thesis will be presented and discussed in chapter eight. I will then move on to chapter nine in which I will conduct a concluding discussion. Here, I intend to address the research questions presented above by combining the findings of the four individual articles with the theoretical framework that I discussed in chapter six.

The last chapter will provide a Swedish summary of the thesis.

4. Huntington's disease

Huntington's disease was previously known as the "dance disease" or "St. Vitu's dance" due to the striking pattern of so called choreatic movements that are part of the neurological symptoms of the disease. In some parts of North Eastern USA, the disease was also called "the migrims" or "the magrums", names that reflect another part of the symptomatology of the disease; mood swings and at times irritability (Wexler, 2008: 18-19). The disease was given the name Huntington's chorea in the late 19th Century after George Huntington who worked as physician on Long Island, mainly around East Hampton where many families were struck by the disease. In 1872, George Huntington wrote a paper, based on his observations of the families that he treated in and around East Hampton, describing and identifying the disease as a genetic disease, with a dominant pattern of inheritance. Huntington's chorea was renamed in the beginning of the 1970s as an acknowledgement of the wide range of symptoms that appear in conjunction with the disease, among which choreatic movements are only one. Apart from these neurological symptoms, Huntington's disease also often gives rise to a variety of psychiatric symptoms such as depression, moods swings and personality changes. In the later stages of the disease there is also often cognitive symptoms, such as dementia present (Petersén, 2001: 16). Today, Huntington's disease is increasingly seen as a both a neurological and a psychiatric disease that involves disturbances of movement, mind and mood (Wexler, 2008: 17-19).

4.1 A late onset disorder

Huntington's disease is a late onset disorder, which means that in a typical case, the first clear signs and symptoms of the disease occur between 35 to 55 years of age; although these figures can vary in each case of the disease (Petersén 2001: 16; Quarrell, 2008: 7). The formal diagnosis of the disease is established when a pattern of clear neurological symptoms are present. However, these neurological symptoms can be preceded by other symptoms

that progress gradually and are initially very subtle. Because of this gradual and subtle progression, the symptomatology of the disease is, in these early stages of Huntington's disease, difficult to distinguish from aspects that can be part of the behaviour of someone who is not affected by Huntington's disease. Oliver Quarrell, a clinical geneticist, points out the ambiguity between normality and abnormality. Due to this, it is only possible to estimate that certain patterns of behaviour within the sick individual were early signs of the disease when more obvious signs, such as clear neurological signs and symptoms, occur later on as the disease progresses into later stages (Quarrell, 2008:6). Today, it is not possible to give any form of exact information as to when the disease will present itself in the form of clear neurological signs and symptoms. In general, individuals who carry the mutation within their genome become afflicted sometime in mid-life and in general die 10-20 years after the appearance of the first neurological symptoms (Kristoffersson, 2010: 94; Petersén, 2001: 16).

4.2 The genetics of Huntington's disease

In addition to this complex symptomatology of Huntington's disease, the disease also contains the prospect of an ongoing continuance in the affected families, as Huntington's disease is a genetic disease. It is a monogenetic disease, which means that it is caused by a mutation in a single gene that is located on Chromosome 4 (Huntington's disease collaborative research group, 1993) that codes for the Huntingtin protein. As already mentioned in the introduction, the mutation displays an autosomal dominant pattern of inheritance; children of affected individuals run a 50% risk of inheriting the gene. If that is the case, they will inevitably fall ill themselves due to the 100% penetrance of the mutation; that is, if you are found to be a gene-carrier for the gene, at one point in time you will fall ill with the disease. The finding of the mutation in 1993 meant that it suddenly existed an option for all those individuals who were at risk for the disease to take a genetic test that gave them a straight answer whether their genome contained the mutated gene or not (Wexler, 1995: 258). Yet, as pointed out by clinical geneticist Ulf Kristoffersson the predictive genetic test can only show whether or not your genome contains the mutated gene, but the test cannot say anything certain as to when you will fall ill with the disease (Kristoffersson, 2010: 94).

4.3 Huntington's disease as a "model disease"

Although it affects few individuals, Huntington's disease has also come to function as a 'model disease' for the medical sciences. It shares clinical features with more common brain disorders such as Alzheimer's disease and Parkinson's disease, for which there are no clear explanations. Due to the discovery of the mutated gene in the early 1990s and the subsequent availability of a predictive genetic test in a clinical setting, Huntington's disease has come to function as a model disease when it comes to social and ethical issues. In particular, it is used as a standard with regard to predictive genetic testing, since it was among the first genetic diseases for which this form of genetic testing became available for individuals at risk (Tibben, 2007; Brouver-Dudokdewit et al., 2002). The strong genetic basis is of course something that clearly separates Huntington's disease from many other and more common diseases in which the genetic component is not as clear as it is in Huntington's disease. Another feature that makes the disease unique is the existing alternative of performing a genetic test in order to find out your genetic status. This alternative for those who are at risk has been present within the context of Huntington's disease for a long time, which is a feature that separates Huntington's disease from many other diseases in which the use of genetic testing remains to be seen.

However, the scientific development within genetics and genomics has also led to an increased knowledge about genetics in conjunction with disease. It has also increased possibilities to investigate the genetic make-up of individuals through genetic tests or screening of the genome. So, depending on how the continuing development within genetics and genomics will affect future medical practice, many of those features that today separate Huntington's disease from other more common diseases might be less pronounced as genetics becomes more regularly used within medicine. There are other features of the disease, however, that are shared with other more common diseases. Huntington's disease is a chronic disease that requires extensive care over a substantially long time. Moreover, the disease also contains symptoms, for example dementia and movement disturbances, that resemble symptoms seen in other diseases. As such, the disease displays features that are similar to other and more common diseases. This becomes clear in relation to such matters as family care giving for the afflicted individual. This is an aspect of the disease that the affected families share with numerous other chronic diseases such as stroke, Parkinson, Alzheimer and other forms of dementia.

4.4 Engagement of the affected individuals

Another important feature of Huntington's disease concerns the involvement of the affected individuals and their families in raising the public awareness for the disease, as well as an extensive engagement in the scientific research on the disease. The origin of this engagement among the affected families can be found in USA, with Marjorie Guthrie as a driving force. She was the wife of the popular American folksinger Woody Guthrie, who suffered from Huntington's disease of which he later died. She founded the lay organization Committee to Combat Huntington's disease in 1967 (Quarrell, 2008: 3). Later on, this organization grew into a national grass-roots organization. Under the new name Huntington's Disease Society of America, extensive work was carried out in order to raise the awareness among the general public for the disease (Wexler, 1995: 15-16). Another important figure was the American psychologist and psychoanalyst Milton Wexler whose wife fell ill with the disease in 1968. This prompted Wexler to organize the Hereditary Disease Foundation in order to support basic research on the disease. As a rare genetic disease, Huntington's disease was, at that time, only of interest to a few specialists working within neurology and genetics, but Wexler and the Hereditary Disease Foundation helped create a support system wherein researchers could obtain financial support, genealogical tables and tissue banks in order to initiate more research (Wexler, 1995: 13, 16). This extensive engagement among the affected families has been, and continues to be, an important factor in the research on Huntington's disease. For example, the hunt for the mutated gene was initiated in close collaboration with patient organizations representing those who were affected by Huntington's disease (Wexler, 1995). So, even in this context of patient or lay engagement in scientific and medical research, Huntington's disease might be considered in terms of a model disease. It forms an example for a broader development of an increased patient and lay engagement within scientific and medical research (see next chapter for a broader discussion of this development).

In the next chapter, I will discuss earlier research performed on Huntington's disease, as well as previous research within the cultural and social sciences on the scientific that have been important for this thesis.

5. Previous research

This chapter opens with an account over previous research performed within the caring sciences on Huntington's disease. At least to some degree, the perspective is slightly different within ethnology, as well as within the other cultural and social sciences. Here, the individual dimension that often stand in focus for research performed within the caring sciences, is more or less shifted towards more general cultural, social and political perspectives at work within culture and society. One good example of this shift towards more general perspectives can be found in research that has its basis in the works of the French philosopher and historian of ideas Michel Foucault (see below and chapter six for previous research and more theoretical discussion of this perspective) that analyse this scientific development through such notions as power and the exercise of power within modernity and the modern society. I will, however start with accounting for research on Huntington's disease performed within the caring sciences, which provided a background for me as I commenced my own fieldwork. After this, I will continue with presenting ethnological research on modernity, as well as research on cultural aspects of health and medicine performed by ethnologists. I will then move on with an account on previous research performed on the scientific development within genetics and biomedicine. Among the vast amount of research performed within the cultural and social sciences, the research that I will present in this section has been important for the process of writing this thesis. I will end the chapter with a discussion on the contribution of this thesis.

5.1 Research on Huntington's disease

The experiences of individuals who are affected in various ways by Huntington's disease have been the focus for a number of qualitative studies performed within the caring sciences. However, most of the studies have investigated these experiences mainly from a personal or individual dimension. The focus for these studies is a number of issues in relation to

the disease. These include predictive genetic testing and being at risk for Huntington's disease (e.g. Hagberg et. al., 2010; Klitzman and Sweeny, 2010; Etchegary, 2009; Futter et. al., 2009; Konrad, 2005; Decruyenaere et. al., 2004; Taylor, 2004; Cox and McKellin, 1999; Bindell et. al., 1998a; Bindell et. al., 1998b; DudokeWit et. al., 1998). Further topics concern reproductive decision-making and responsibility (Quaid et. al., 2010; Downing, 2005; Konrad, 2003) and the impact of Huntington's disease on the family (Brewer et. al., 2007; Smith et. al., 2006; Brouwer-Dudokewit et. al., 2002; Sobel and Cowan, 2000a; Sobel and Cowan, 2000b). Young people's experiences of growing up in a family affected by Huntington's disease are examined (Forrest Keenan et. al., 2009; Williams et. al., 2009; Forrest Keenan et. al., 2007), but also issues of stigmatization and discrimination (Penziner et. al., 2008; Bombard et. al., 2008; Bombard et. al., 2007; Etchegary, 2007). Other studies include matters concerning communication about the disease (Hartelius et. al., 2009; Forrest, 2003). Moreover, some studies have addressed the existential aspects of HD (Huniche, 2009).

Huntington's disease has also caught the attention of a number of scholars working within the social and cultural sciences. In this context, I would like to mention two researchers whose works have been important for me. The English anthropologist Monica Konrad has investigated issues around predictive genetic testing, taking an interest in the implications of this medical technology, especially in relation to differences between the experiences of the affected individuals and the knowledge and perspectives of this diagnostic technology provided by medical experts (Konrad, 2005). Another important influence has been the works of the American historian Alice Wexler, who also has a personal history of Huntington's disease, as her mother suffered from the disease. On the basis of her personal experiences, she has written an biographical account of her family's and her own experiences of being at risk and the process of decision making as to whether or not to go through with a predictive genetic test in order to find out if she was a gene carrier for the mutant gene. This biographical account is also a very good account of the efforts among researchers, patients and patient organizations that led to the localisation of the mutated gene, and subsequently to the introduction of a predictive genetic test for Huntington's disease within health-care (Wexler, 1995). In addition to this biographical work, Wexler has also carried out historical research about the history of Huntington's disease in America (Wexler, 2008).

Apart from this research on Huntington's disease, a vast amount of research of importance for this thesis has been performed within ethnology, as well as within and other disciplines of the cultural and social sciences. This

research has not been focused upon Huntington's disease, as with the research performed within the caring sciences. Rather, as I mentioned in the beginning of this chapter, it has investigated general aspects of health and medicine as part of our culture. In addition to this research about cultural and social aspects of medicine, the issue of modernity has also been a significant field of ethnological research. Considering the aims of this thesis, I intend to continue with an overview of these two ethnological research fields. I will begin with ethnological research on modernity and the modern society.

5.2 Ethnological research on modernity, health, and medicine

Considering the aims of this thesis, various ethnological investigations on modernity and its various features also have an importance for this thesis. Here, Jonas Frykman has done research on the intersection between the male body, experience of pain and modernity (Frykman, 1998). Much interesting ethnological research has been focused upon various aspects of the Swedish welfare state, and the transformation that the Swedish society went through following the development of the welfare system. Ethnologist Karin Salomonsson has from a historical perspective investigated the everyday situation for social care workers, a professional group that was essential in the machinery of the welfare state (Salomonsson, 1998). This professional group was also in focus for Karl-Olov Arnstberg who through interviews investigated their working situation (Arnstberg, 1989). Another interesting thread of previous ethnological research on modernity concerns the meeting between citizens and various public authorities. For example, ethnologist Birgitta Svensson has investigated the encounter between the Swedish travellers (tattare) and the Swedish modern society (Svensson 1993). Lena Gerholm points to how the meeting between citizens and public authorities might be founded upon different perspectives about those issues around which they meet (Gerholm, 1985). Jonas Frykman and Kjell Hansen have performed research on the relationship between Swedish National Insurance Agency and its clients (Frykman and Hansen, 2005).

Health and medicine has for a long time been an important research field for ethnology. Ethnologists Gabriella Nilsson and Kristofer Hansson note that the point of departure for an ethnological investigation of health and medicine often concerns the various cultural processes wherein

representations about such aspects as life, death, healthy and unhealthy are constructed culturally (Nilsson and Hansson, 2011: 195). Previous research within ethnology covers a vast amount of issues that arise in relation to medicine and medical practice, including cultural representations about the normal and pathological (e.g. Hammarlin, 2008; Gerholm, 1993), the practice of medicine within a multicultural society (e.g. Wolanik Boström and Öhlander, 2011; Fioretos, 2009), ageing (Alftberg, 2012), active patienthood and self-care (Alftberg and Hansson, 2012; Gunnarson, 2011), or the meeting between asthmatic adolescents and care giving personal within Swedish health-care (Hansson, 2007). The intersection between body, health and well being has been the focus for ethnological research by Tom O'Dell, who looks upon the way wellbeing and health have been understood and acted upon in various commercial settings such as hotels and spas (O'Dell, 2010). Yet, the historical perspective has, more or less, always been important for ethnology, and among the research performed within the discipline upon cultural aspects of health and medicine there can also be found research that take a historical perspective in order to investigate how the cultural understanding of health, disease and medicine has changed over time (e.g. Idvall, 2011; Jönsson, 2011; Frykman, 1994).

Apart from the ethnological research that I presented above, cultural and social aspects of genetics and biomedicine has also been the subject for ethnological research. Malin Ideland has investigated how the scientific developments within genetics has been covered and presented in public media (Ideland, 2002). In a number of works, ethnologists Susanne Lundin and Lynn Åkesson have studied various aspects of the scientific development within genetics and biomedicine. Their work spans various issues that have gained importance during this scientific development, ranging from cultural perspectives on genetics, public reactions and understanding about gene-technology to reproduction in the age of biomedicine. Further, they have examined the implications of the scientific development within not only genetics but also biomedicine in general, regarding the way we perceive our body (Lundin and Åkesson, 2000; Lundin, 1997a; Lundin, 1997b; Åkesson and Lundin, 1996; Lundin, 2004). One important point made by this ethnological research concerns the intertwining that exists between science and culture, a sort of intertwining that shapes public understanding about genetics (Lundin and Åkesson, 2000). This aspect within ethnological research on genetics and biomedicine has been an important influence for me in relation to my interest in genetic diseases and modernity.

5.3 Previous research on cultural, social and political aspects of genetics and biomedicine

Among the vast amount of research performed within the cultural and social sciences on the scientific development in genetics and biomedicine, those that revolves around the perspective offered by the French historian of ideas and philosopher Michel Foucault was important in the initial stages of my work with this thesis. Foucault's ideas and concepts upon the exercise of power within modernity have inspired research in various disciplines, including ethnology (e.g Lennartsson, 2002; Drakos, 1997; Svensson, 1993). The importance of Foucault's work comes about in relation to his notion of power, and his influence on cultural and social research about genetics and biomedicine has been substantial (e.g. Petersen and Bunton, 2002; Gottweis, 1998; Lupton, 1995). For example, the Danish anthropologist Klaus Hoeyer has investigated bioethics and its role within regulation of genetics and biomedicine on the basis of Foucault's theories of power and the exercise of power (Hoeyer, 2004). One of the most influential interpreters of Foucault's work in conjunction to genetics and biomedicine is the English sociologist Nikolas Rose, who has investigated the implications of the scientific development within biomedicine by applying some of Foucault's influential thoughts on power (see chapter six for a more detailed discussion of this analytical framework) (e.g. Rose, 2007; Rabinow and Rose, 2006).

Another important interpreter of Foucault's work is the American anthropologist Paul Rabinow, whose anthropological research on the cultural and social aspects of the scientific development within biomedicine and biotechnology has ranged from the introduction of novel theoretical concepts to empirical investigations (Rabinow, 2008, 1999, 1996). One important aspect of Rabinow's work concern how knowledge within genetics and biomedicine gives rise to new social formations. These new social formations arise on the basis of what Rabinow denotes as biosociality, which are social formations that forms and take shape around various issues that are connected to genetics and biomedicine (Hagen, 2012; Rabinow, 1996). An additional thread of previous research concerns these various sorts of collective mobilizations among affected individuals; for example through the various activities of patient organizations and other

forms of health-activism (e.g. Gibbon and Novas, 2008; Rose, 2007: 131-154; Rose and Novas, 2005; Heath, Rapp, and Taussig, 2004).

5.4 The contribution of this thesis to previous research

On the basis of the aims and research questions of the thesis, it is my intention to make a contribution both to the research on Huntington's disease and to ethnological research on health and medicine. My aim is to provide an analysis that integrates the personal dimension, which stands in focus for much of the previous research performed on this disease, with perspectives from the cultural and social sciences, accentuating the general socio-cultural context. In my case, this general socio-cultural context consists of modernity, which I see as important in order to fully understand the situation that the affected individuals face when they are confronted with Huntington's disease. With regard to the previous research performed within ethnology, this thesis intends to make a contribution to the existing research on health and medicine. In relation to the ethnological research, I see it as important to achieve a deeper knowledge around the relation between everyday life with a disease and those cultural patterns of modernity that stand in focus for this thesis. By delivering such knowledge, I hope to extend the existing research interest within ethnology on modernity to encompass ethnological research on cultural aspects of health and medicine. However, I also intend to approach this contribution from a slightly different angle than the influential position attained by the perspectives that are inspired by Michel Foucault. By doing so, it is my hope that this thesis will provide a more "fine-tuned" analysis, which enables us to a better understanding of the complexities that exist in relation to the scientific development within genetics and biomedicine.

In order to fulfill these intentions, I need to discuss the theoretical perspective, and in the next chapter my choice of theoretical framework will be presented and discussed.

6. Theoretical framework

My choice of theoretical framework is guided by the aims of the thesis, which involve both the level of everyday life and the wider socio-cultural level of modernity and the modern society. Whereas the level of everyday life is investigated through my ethnographic material, the theoretical framework will address different aspects of modernity. The main part of my theoretical framework is based upon on a figure of thought about Western culture and society that has been part of the cultural and social sciences since the 19th Century. As argued by sociologist Johan Asplund, perhaps such ideas have been included in these disciplines even longer than that, moreover in cultural spheres other than the Western culture (Asplund, 1991: 21-22). The German social philosopher Fredinand Tönnies is arguably, one of the first thinkers to conceptualize the general cultural patterns of modernity, from which the scientific problem addressed by this thesis, arises. Through his well-known concepts of Gemeinschaft and Gesellschaft, Tönnies tried to capture emerging aspects within modernity, which cultural theorist Johan Fornäs terms differentiating universalization (Fornäs, 1995: 31; Tönnies 1887, 2001). Modernity, writes Fornäs, has a universalizing tendency, not least through the present forces of globalization. Today, certain features of life, culture and society within modernity can be discerned everywhere in the world (Fornäs, 1995: 30). Yet, and more important in relation to this theses, these tendencies of universalization are based upon a process that goes in the other direction, towards a growing universal differentiation. This process entails a growing differentiation between different cultural and societal spheres, such as art, science, religion and politics, as well as different types of human action (Fornäs, 1995:31). Tönnies was among the first classical thinkers to conceptualize this aspect within modernity. Nevertheless, as pointed out by sociologist Bo Isenberg, even if the process that Tönnies captured through his concepts still attains a value, there might be other approaches to this process that are more accurate (Isenberg, 2001: 51).

Pushing the Gemeinschaft and Gesellschaft distinction further, Jürgen Habermas makes a similar distinction as Tönnies as he analytically views the modern society in terms of lifeworld and system (Habermas, 1984,

1987). In relation to the aim of the thesis, this framework will then enable me to address and explain how these everyday lifeworld experiences of the disease are challenged by more "systematic" perspectives; these subsequently give rise to the ambivalence and ambiguity that is contained within the ethnographic material.

There are of course alternatives to Habermas' theoretical account. Most notably is perhaps the account that stems from the French philosopher and historian of ideas Michel Foucault. Two of the most used concept developed by Foucault is biopolitics and biopower. The most coherent definition of these two concepts can be found in the first volume of the *History of Sexuality* (Foucault 2002), wherein Foucault outlined a change in political objectives and the way power is exercised in the modern society. The main feature of this change in political objectives and the exercise of power concerned a resolve to "maximize life" through a proper administration, regulation and control of the population (Kalm, 2008: 69-78; Foucault 2000: 326-348, Dreyfus and Rabinow, 1983: 104-205). In line of this shift in political objectives, a whole range of institutions are founded, among others public health or social medicine, all of which Foucault traces to this new biopolitical objective to "maximize life" within the population (Foucault, 2000: 134-156). Another feature of this change concerns the way power is exercised. In line with this change towards a "maximization of life", new forms of practices are introduced in order to regulate, control or discipline the way the individual make use of his/hers body. The purpose of these novel institutions and disciplining practices is, according to Foucault, to increase the ability of the sovereign or the bourgeoning nation state to increase the productivity harbored among its subjects and citizens in a rational and effective way (Foucault, 2000: 140-142).

Drawing upon Foucault's ideas of how power is exercised within modern society, sociologist Nikolas Rose argues that genetics and such adjacent disciplines within biomedicine as neuroscience will make an impact on our culture and society by providing new and powerful representations of ourselves. These representations entail new ways of seeing, judging, and acting upon human normality and abnormality. It enables us to be governed in new ways. And it enables us to govern ourselves differently (Rose, 2007: 192). Here, Rose conceptualizes the impact of new biological knowledge through such concepts as 'somatic individuality' and 'neurochemical selves' (Novas and Rose, 2000; Rose, 2007: 187-223). The question that we might ask ourselves in relation to this argument is what happens when these thoughts and concepts is applied in the micro-level of everyday life. I will come back to this question at the concluding part of the thesis. The major

limitation to the framework provided by Foucault is its major focus upon power and the exercise of power within modernity. Although this framework provide several major insights and new opportunities for investigating power, it nevertheless revolves around the encompassing feature of power, something that makes it a rather blunt analytical instrument for the type of investigation that I intend to perform in this thesis. The linkage between everyday life with a genetic disease and intrinsic patterns of modernity contains a complexity that are not fully acknowledged by a that kind of emphasis upon power that are the point of departure for Foucault. Moreover, the sort of analysis performed by Foucault did take, as its objectives, to analyze changes that took place very much at the macro-level of the society; the way the perception of madness, punishment and sexuality has undergone changes during the history. It is therefore a theoretical framework that leaves a rather small possibility to address issues that comes forward on the micro-level that ethnographic investigations focus upon as an important part of their research. I mean that Habermas' distinction between lifeworld and system provides a theoretical framework that will enable me to address the complexity that are contained within the ethnographic material, as well as to address the linkage between the micro and macro levels that are the main objective for this thesis.

In the rest of this chapter, I intend to present and discuss these two concepts, but I will also supplement Habermas' theory with additional perspectives that will enable me to address the aims and research questions of the thesis in a more accurate manner. These additional perspectives will be derived from various sources. Influences come from the physician and philosopher Drew Leder's writings on embodiment (Leder, 1990), as well as from philosophy of science and history of science. With regard to the latter perspective, I will rely upon the French philosopher Gaston Bachelard's writings on epistemological obstacles and the German historian Hans-Jörg Rheinberger's outline on experimental systems (Bachelard, 2002; Rheinberger, 1997). I will also use the post-colonialist theoretician Homi. K. Bhabha' s "Third space" concept as I discuss the sharp and dichotomous relationship between lifeworld and system that are given through Habermas' theory (Bhabha, 1994).

6.1 Lifeworld

The concept of the lifeworld originates with Edmund Husserl, the founder of the philosophical phenomenological tradition, which takes the human

experience as its object of knowledge. Husserl´s philosophical project came to focus on the issue of epistemology and the foundations on which our knowledge can be trusted. Originating from Husserl's epistemological inquiries, the phenomenological tradition branched out in many different directions, with different emphasis. However, they have all tended to share a common interest in the uniqueness of the human experience, especially of the things which matter for us, and which constitute our lived world (Smith, Flowers & Larkin, 2009: 11). One important source for Habermas' understanding and use of the lifeworld concept stems from the work of sociologists Alfred Schutz and Thomas Luckmann (Habermas, 1987: 126-132). Applying Husserl´s phenomenological philosophy and the lifeworld concept as a way to explore the province of sociality and culture, Schutz and Luckmann consider that our lifeworld could be seen as a background (Schutz and Luckmann, 1973). This background consists of a number of presuppositions and patterns; Schutz and Luckman define these as the natural attitude, on which our everyday experiences of reality are founded.

'The sciences that would interpret and explain human action and thought must begin with a description of the foundational structures of what is prescientific, the reality which seems self-evident to men remaining within the natural attitude. This reality is the everyday life-world. It is the province of reality in which man continuously participates in ways that are at once inevitable and patterned' (Schutz and Luckmann, 1973: 3).

Returning the issue of everyday reality, they state how everyday life can be seen as a pregiven domain that are experienced in a direct way on the basis of natural and social fundamentals:

'Everyday life is that province of reality in which we encounter directly, as the condition of our life, natural, social givens as pregiven realities with which we must try to cope' (Schutz and Luckman, 1983:1).

Ethnologist Mia-Marie Hammarlin makes a similar definition as Schutz and Luckmann when she defines the lifeworld as the lived existence, which precedes the sort of abstraction that forms the basis for the production of scientific knowledge. In the same way as a map is an abstraction of the physical landscape; science is an abstraction of the lifeworld (Hammarlin,

2008: 31). Individuals come to an understanding about matters in their objective, social, or subjective worlds mainly through these prescientific patterns, the lived experience (Habermas, 1987: 126). This background is, moreover, also the foundation upon which 'the communicative practice of everyday life' rests (Habermas, 1987: 133). And it is this sort of coordinated action among individuals that Habermas defines as communicative action (Habermas, 1987: 135-137).

Still, this thesis revolves around the body, which has not been specifically addressed in my discussion about the natural attitude serving as a foundation for the lifeworld. In order then to complement those definitions given above, I intend to make use of an additional outline provided by Drew Leder, who focuses upon the absence of our bodies within our everyday life.

6.1.1 Lifeworld and the absent body

Drew Leder's point of departure is that human existence is incarnated. Building on the works of such philosophers as Maurice Merleau-Ponty, Leder's investigation of human embodiment takes a slightly different route than those previously examined by Merleau-Ponty. In contrast to Merleau-Ponty, whose focus was mainly concentrated upon those parts of our bodies that we have a direct experience of, Leder focuses upon those part of our body that recede from direct experience (Leder, 1990:1-2). This absence of our body can manifest itself in different ways, ranging from the kind of absence that we experiences when we are in the midst of an activity, for example, reading a book or writing an academic article. During such activities, and in fact during most of our everyday life, our bodies are not present; our embodiment recedes from our attention in favour of the activities that occupy us at the moment. This occurs despite the formative role of the body for all these activities, through senses etc (Leder, 1990: 1). However, even if it seems absent within our everyday life, in many cases the body can and does become part of our direct experience, for example, when we for various reasons experience pain. Leder analytically conceives this circumstance of absence and presence as a dialectical relationship; engaged, as it is, in continually leaping out into direct experience and falling back again (Leder, 1990: 103, 106).

In relation to the parts of our bodies that we encounter within the context of Huntington's disease, the genes, there is another part of Leder's outline that becomes important. This part addresses those parts of our body that always are hidden from our direct experience, those parts that are located within

our corporeal depths. Here, the term depth signifies both a physical location as the body contains a number of internal organs and processes that are hidden under the surface of the body. But, the term depth also signifies that these organs and biological processes constitute a hidden depth in relation to us as those who experience (Leder, 1990: 36). Some of these organs and biological processes are of course not totally hidden from our direct experience. Nevertheless, the perception of these inner parts of our body is limited in comparison to those perceptive capabilities that are directed towards the external world surrounding us. And, when it comes to such parts of our bodies as genes and molecules, we encounter what Leder calls a 'phenomenological nullpoint' (Leder. 1990: 43) that are parts of our body, which we have no direct experience of, hidden as they are deep inside our body.

In view of the outline of the lifeworld given above, Drew Leder's reasoning about the absent body, and especially of those parts of our bodies that are phenomenological nullpoints, points to how these phenomenological nullpoints constitute a dimension of our lives. This dimension is not self-evident in comparison to other parts of the lifeworld, for example those parts of our body that we have a direct experience of. These phenomenological nullpoints, for example our genes, thus constitute a very elusive and abstract dimension; to a large extent, this is not given to us in such a self-evident or pre-given way as Schutz, Luckmann and Habermas take as their point of departure. And it is this situation that we are confronted with within the context of a genetic disease such as Huntington's disease, in which this self-evident and pre-given natural attitude is challenged in various ways.

6.2 System

Drawing on the work of sociologist Talcott Parsons and his functionalist theory, Habermas establishes the system as an analytical counterpart to the lifeworld (Habermas, 1987:199-203). A system is often understood as consisting of several parts, which are well ordered and in some respect autonomous and self-reproducing (Fornäs, 1995: 53). It is this autonomy and the self-reproducing features of the system that set it apart from all those individuals that make up parts of the system; for example, welfare administrators within the welfare system. The abstract notion of the system

can be seen as a counterpart to the lifeworld. Many of the elements contained in the lifeworld are given new meanings and functional roles within the system. As in the case of Tönnies' differentiation between Gemeinschaft and Gesellschaft, the differentiation between lifeworld and system constitutes one important and fundamental hallmark of modernity and the process of modernization. The overall organization of the pre-modern society was based on the lifeworld; tradition and religion exercised a normative and existential framework permeating nearly all aspects of the society. The main impact of modernity is the expansion of rational thinking; in the form of science, the free-market economy and the rule of law, this broke the pre-modern hegemony of tradition and religion. This development also gave rise to a structural change in the form of a wide-ranging differentiation of the society into different systems rooted in an instrumental mode of rational calculation (Crossley, 2005: 323).

The two most obvious examples of systems are, arguably, the economic system and the bureaucratic system of the state, particularly the welfare state. In the latter, the societal function is to provide social stability through allocation of resources to the citizens. Here, the appliance of instrumental rationality is necessary in order to allocate resources in an effective and fair manner to those who are entitled to these resources. However, as pointed out by Habermas, this form of instrumental rationality does at times come into conflict with those self-evident and pre-given presuppositions that guide both understanding and action within the lifeworld (Habermas, 1987: 332-373). The differentiation between lifeworld and system is given a rather sharp and dichotomous character by Habermas, a sharp distinction that leads to confrontations. These sorts of confrontations between lifeworld and system constitute an central aspect of modernity that is seen as coinciding with ambivalence (e.g. Weber, 1979; Bauman, 1991; Fornäs, 1995: 27). Within Habermas's theoretical framework, this ambivalence is often linked to his discussion about a situation in which the system colonizes the lifeworld. This colonization means that the instrumental and strategic incentives of the system block or even displace the sort of understandings that is part of the lifeworld (Habermas, 1987: 332-373).

In relation to the question of system colonization of the lifeworld, it is important to acknowledge the criticism that exists upon this aspect of Habermas' theoretical framework. The American philosopher Andrew Feenberg sums up this line of criticism by declaring that the differentiation of systems from the lifeworld is nowhere near as complete as Habermas assumes (Feenberg, 2010: 174). Although Habermas' theory is still valid as a theoretical framework that captures the essential aspects of modernity, this criticism raises the important question of the sharp and dichotomous

distinction between lifeworld and system. In the last chapter of the thesis, instead of this sharp and dichotomous relationship between lifeworld and system, I will argue for a more gradual differentiation between these two features of modernity. This argument is of course something that needs to be founded theoretically, and I will make use of a perspective that has its origin in a number of perspectives, including post-colonial studies, sociology, as well as cultural geography. The mutual line of these clusters of perspectives is that they emphasize the notion of the "Third" as such a theoretical perspective that will enable studies of cultural and social issues to move away from viewing these issues solely in terms of sharp dichotomies. Consequently, within this cluster we find such theorists as the post-colonialist theoretician Homi. K. Bhabha, who conceives the meeting between two social groups with different traditions and potentials of power as a special kind of negotiation, or translation, which takes place in a "Third space" of enunciation (Ikas and Wagner, 2009: 2). Bhabha sees the meetings and negotiations that take place within this "Third space" in terms of an empowering hybridity, where opposing cultural practices and cultural identities are combined with each other (Ikas and Wagner, 2009:2; Bhabha, 1994:20). Likewise, we find the same line of thinking in the American geographer Edward Soja's writing about space and spatiality (Soja, 1996). Inspired by the writings of the French sociologist Henri Lefebvre, Soja argues for the importance of space and spatiality when considering various aspects of human existence. According to Soja, our existence involves social, historical but also spatial dimensions; the latter has too often been overlooked and placed in the periphery in various attempts to understand and analyse human existence (Soja, 1996: 70-71; Lefebvre, 1991). In relation to the issue of sharp dichotomies, Soja's intention is to introduce the notion of spatiality as a "Third" dimension alongside the two previous and dominating perspectives of sociality and history when it comes to the essential characteristics of human existence (Soja, 1996). Returning to the lifeworld and system perspective that I employ in this thesis, these theoretical arguments, discussed above, offer an opportunity for a discussion that presents a slightly revised perspective on the lifeworld/system dichotomy. This discussion will be part of the last and concluding chapter in the thesis.

Before moving on to next chapter, in which I will discuss the material and methods of the thesis, there is another issue that needs to be addressed. This issue concerns the question of genetics and the way I intend to incorporate genetics within the general framework that I have presented so far in this chapter. The focus for Habermas is firmly set on economy and bureaucracy as prime examples of system formation within our culture and society, but

Habermas is less clear about how we can understand science as a form of system. Such an outline is indispensable in order to achieve the aims and to answer the research questions of the thesis. In order to provide such an outline I will complement Habermas' theory with an additional account given by the German historian Hans-Jörg Rheinberger, and the French philosopher Gaston Bachelard.

6.2.1 Experimental systems

By using the term experimental system to capture the workings of the natural sciences, Rheinberger focus on the practical aspects of the production of scientific knowledge. The advantage of this characterization of scientific production is that the concept ties together, not only those features that we normally connect with the production of scientific knowledge such as theories, hypotheses and experimental testing of these hypotheses, but also such important and essential aspects as instruments, measuring devices and other contrivances of various kinds. Moreover, these experimental systems incorporate social and institutional aspects that give coherence to the activities of the researchers working within these systems, at the same time setting up boundaries in relation to other experimental systems (Rheinberger, 2004: 3). These experimental systems have a number of characteristics. They are the smallest integral working units of science, around which the research is set up in order to provide answers, but also to generate new research questions. Furthermore, in accordance with the definition of a system given previously in this chapter, this view of science in terms of systems sets the production of scientific knowledge somewhat apart from the individual scientists, who are part of these systems.

According to Rheinberger, a scientist or a group of scientists rarely conduct isolated experiments in relation to a theory. Instead, the production of scientific knowledge grows through a system of experiments that is designed to yield new knowledge (Rheinberger, 1997: 27). Often this new knowledge is produced through an intertwining between research objects, for example genes and the technical objects used within the experimental set-up. Thus, these experimental systems are 'a kind of dynamic research bodies that convey material shape to the scientific objects formed within them' (Rheinberger, 2004: 4). Within the life sciences, including genetics, one crucial feature of these experimental systems is their utilization of model organisms. As I will show in chapter nine, during its entire existence as a scientific discipline genetics has been dependent upon various model organisms in order to produce its scientific knowledge. The basic

assumption behind this epistemological approach is that all organisms share a certain extent of specific aspects that have been conserved during evolution. With the introduction of molecular biology in the end of the 1940s and its subsequent dominance, this epistemological approach became one of the cornerstones within various scientific initiatives, eventually yielding the structure of DNA and the composition of the genetic code (Kay, 1993; Rheinberger, 2004).

Yet another, and for this thesis, crucial feature of those experimental systems is that these systems also incorporate an abstraction of the natural attitude of the lifeworld. Gaston Bachelard sees this abstraction as necessary in order to achieve a rational scientific approach, or as Bachelard puts it, a scientific mind (Bachelard, 2002). In relation to the lifeworld, Bachelard sees its pre-given and self-evident attitude as an obstacle for the formation of the scientific mind.

‘In the formation of a scientific mind, the first obstacle is primary experience, the experience we place before and above that criticism which is necessarily an integral part of the scientific mind’ (Bachelard, 2002: 33).

The natural attitude of the lifeworld is then, according to Bachelard, an epistemological obstacle that needs to be overcome in order to arrive at scientific knowledge. And, as I will come back to in chapter nine, this is very much the case in conjunction with the scientific development within genetics. From an analytical viewpoint, genetics constitutes an experimental system that has been exceedingly successful, from its very beginning, in producing scientific knowledge. However, this success constitutes a challenge in relation to the everyday experience among the individuals that I met and interviewed during my fieldwork. These experiences are the focus for each individual article, and in the next chapter, I will discuss the methods and the material of the thesis.

7. Methods and Material

The ethnographic material was obtained through my fieldwork that took place in 2009-2010 with eleven individuals who in various ways are affected by Huntington's disease. This fieldwork mainly consisted of interviews, but it also contained my participation in meetings with a local support group in the Southern parts of Sweden. The participants of the study were recruited either through personal visits to both national and local meetings for individuals and families affected by Huntington's disease or through advertisement on websites for Huntington's disease. In conjunction with these meetings, I personally gave information upon the project, but I had also prepared information about the project that I handed out to those who expressed an interest in the project, or those who wished to become a participant and see me for an interview (see appendix). Because Huntington's disease is a sensitive and difficult topic for many affected individuals, the decision was taken to conduct interviews only with those individuals who came forward as a result of the advertisement in which I presented my project and those who contacted me after the meetings that I took part in. All of those who expressed a wish for taking part in the study were sent additional information (including an informed consent; see appendix). Besides this information, they were given time for further reflection on their participation and time to fill in the informed consent. By adopting this rather passive approach in relation to the recruitment of participants, the risk for adverse reactions due to the sensitive topic were seen as being reduced; all participants having time to reflect about their participation. This procedure resulted in the recruitment of eleven participants who are affected by Huntington's disease in various ways. The study includes family members, individuals who were at risk for the disease, and individuals who had gone through genetic testing, as well as individuals who had reach that stage in the disease when they had neurological symptoms. The participants of the study represent a cross-section of the various ways individuals can be affected by the disease, which provides an opportunity to give a general overview of HD.

7.1 Method

In this section, I will go into a more detailed methodological discussion in relation to the interviews. I will begin with an account of how these interviews were performed, followed by a discussion of the process of transcribing and the subsequent analysis of the interviews. Finally, I will discuss the ethical considerations of the thesis.

7.1.1 Semi-structured interviews and observations

The major part of the ethnographic material was obtained through semi-structured interviews. The interviews lasted between 1 hour, 30 minutes and 2 hours, 30 minutes and were conducted in a place of the interviewees' choice. The possibility of letting the participants choose the actual place of the interview came about as a way to even out the differences, as far as possible, in a relation of power that might exist between researcher and participant. By letting the participants choose where they wanted us to meet, the interview could be conducted in a place where they felt at home and secure; a place where I came to them, instead of the other way around. Most of the interviews were conducted in the home of the participants. An interview-guide was employed for the interviews, but it was used in a flexible way; the interviewees could approach various aspects regarding their experiences of Huntington's disease on their own terms. I compiled the interview-guide before the start of the fieldwork, and the construction of the interview-guide was partly informed by issues raised by previous research on Huntington's disease, and partly informed by previous research performed within ethnology. Consequently, this interview-guide can be said to contain parts of my pre-understanding of Huntington's disease, for example in relation to the themes and questions that I chose to include in the guide. However, as I pointed out above, the interview-guide was employed in a flexible manner. Moreover, in the interviews conducted at a later stage in the fieldwork, I occasionally approached issues that had been raised in previous interviews, issues that were not part of the original interview-guide. This strategy enabled me to localize and explore themes in

the illness narratives that I had not been aware of at the start of my fieldwork.

All interviews were recorded by the use of a digital voice recorder. Subsequently, I transcribed all interviews myself in verbatim. In addition to the use of a tape recorder, I also used a field diary, in which I recorded my immediate observations and reflections straight after the interviews. These observations became an important tool in order to comprehend the interview in terms of a social meeting between two individuals. A social meeting that was influenced by such features as emotions (both mine and the participants), the interaction between interviewer and interviewee and the place were the interview took place. The observations provided me then with an opportunity to reflect upon the actual interview situation, including aspects beyond what was being said, my own position as a researcher in relation to the participants, methodological and ethical issues. In many cases these observations and notes also gave me an option to compare and compile, not only what came up during the actual interview, but also similarities and differences between the different interviews. As to my participation in the meetings with the local support group that I followed as an additional part of my fieldwork, I did not use the tape recorder. Instead, in this context I relied solely upon the observations that I made during the meetings. During the meetings, I wrote down the main points of my observations, which were compiled to a more coherent account immediate after the meeting ended. In the same manor as was the case with the interviews, this compilation of the main points into a more comprehensive account enabled me to reflect upon the meetings, as well as to compare these observations with the material from the interviews.

7.1.2 Transcribing and analysing the interviews

Transcribing recorded material into text is an essential aspect of ethnographic methodology and an important step in the interpretative process. Following the French philosopher Paul Ricoeur's argument about the hermeneutical process, transferring the recorded spoken material into written material can be seen as fixation. The spoken word, the discourse as Ricoeur terms it, becomes fixated in writing when the recorded material is transferred into a written format (Ricoeur, 1981: 91). However, this transfer, this fixation, also implies a process of distantiation in which the spoken discourse attains autonomy from its original context. In relation to the hermeneutical process, Ricoeur suggests a process of

decontextualisation and recontextualisation whereby the work to be interpreted transcends its original setting and opens itself up for various ways of reading and understanding (Ricoeur, 1981: 91). From this follows that the process of transcribing the spoken recorded material from the interviews constitutes an important step in the analysis of the interviews. I transcribed all interviews myself, thereby fixating the spoken words of the interviews into a written format. Moreover, this transfer also constituted a gradual distantiation relative to the immediacy between the participants and myself, which was a natural part of the face-to-face encounter of the interview.

The analysis for the transcribed interviews took place in successive steps: First, each manuscript was read several times until a number of themes were identified. Next, the different manuscripts were compared with each other with respect to these themes. In the third successive step of the analysis, a table of overarching themes was organized, which represented the results of the comparison made in the second stage of the analysis. In the last stage of the analysis, these overarching themes were related to more general cultural and social theoretical frameworks. From a more epistemological point of view, this process should be seen as an on-going process of decontextualization and recontextualization. Such an on-going process of decontextualization and recontextualization enabled me to discern the dominant themes within the participants' illness narratives. It also clarified how these themes could be understood and how they might be explained through cultural and social theory. This process of decontextualisation and recontextualisation can be understood as the hermeneutic circle, in which the researcher tries to understand a text, or some other work, by moving between individual parts and the whole, and then back again to the individual parts (Smith, Flowers and Larkin 2009: 34-37; Ricoeur, 1981: 91). This analytic circular movement characterizes my work with this thesis.

7.1.3 Ethical considerations

The regional ethical committee at Lund University approved the project. This means that before my fieldwork, I had to reflect upon ethical issues accompanying a project that is concerned with sensitive issues. The main point of these measures is to protect the participants; the application for

ethical approval is an instrument designed to prompt reflection on various ethical issues of the research before commencing the actual fieldwork. During this period, decisions were made about the procedure of recruiting participants for the interviews. In this process of recruitment, I decided against collaboration with medical institutions. I did not want potential participants to feel obliged in any way to take part in the project, which might be liable to happen if advertisements for the project were placed in waiting rooms or were handed over by health-care personnel. Instead, the choice was to rely on those approaches that I mentioned above.

Before the interviews, every participant signed an informed consent about their participation in the project. Here, they were informed about the nature of the project, their rights as participants and the way the interviews and the project were to be conducted. As pointed out above, all participants were given time, after the initial contact was made, to reflect and think through their participation. The majority of the participants were recruited through the personal visits that I made before commencing the fieldwork, which gave them an additional chance to meet and talk to me personally before deciding if they wanted to take part in an interview. I was sometimes approached by individuals who wanted to take part in the project, but who were at a difficult stage in their life relative to Huntington's disease. When this happened, I decided to refrain from further contact. I am not a trained health-care worker and the difficulties that faced these individuals should be given the attention of trained professionals.

The interviews also meant that a number of ethical considerations had to be regarded and handled. In many ways interviewing can, as pointed out by sociologist and anthropologist Charlotte Aull Davies, be sensitive to differential power relationships. These differences can be linked to various social differences between the researcher and those who participate in an interview (Aull Davies, 2008: 120). In relation to this project, one very important aspect associated with a difference in power between the participants and my part as a researcher concerned the very personal nature of the topic and the exposure that the participants might feel during and after the interview. Thus, in order to avoid a situation in which the participants would feel exposed during and after the interviews, I took on a number of measures. First, I decided to be very open about myself and my own history as a member of a family stricken by disease. As a member of such a family, I took part in providing family care for a relative suffering from illness and faced a number of difficulties, which in certain ways resembled those faced by the participants. By being so open about my own life history, I also exposed issues and parts of myself that were very private for me, which established a potential for equalizing the differences in

power that might arise in relation to the interviews. In addition, immediately after the interview, I reported back to the participants, telling them which aspects within their narratives that I found interesting. This immediate report gave the participants the opportunity to get an understanding of my immediate reactions on their narratives. During the interviews, I also went to great lengths to be as supportive as I could towards the participants, making certain that they could decide for themselves if they wanted to pursue various topics, if they wanted to take a break or terminate the interview. Finally, the participants have been provided the opportunity to ask questions and to react upon the written text.

In order to protect the privacy of the participants, I kept the digital tape recorder where the interviews were stored, the transcribed interviews and all the hard-drives, on which the transcribed interviews were saved, in a locked compartment in my office during the project. Nobody else had access to this locked compartment, and I am the only person to have seen the transcribed interviews. Moreover, all the names of the participants have been changed in the final manuscripts in order to protect the anonymity of those who feature in the text.

7.2 Material: Illness narratives

In this section, I will discuss and problematize various aspects of the empirical material of the thesis. In particular, I will discuss some epistemological aspects that arise in relation to illness narratives, which are the main empirical material obtained through the interviews, and upon which this thesis is based upon. The discussion about these epistemological aspects leads into a subsequent reflection on the limitations of the thesis.

7.2.1 Illness narratives

Sociologist Arthur Frank means that illness narratives have a crucial role in the formation of how we come to experience being ill. According to Frank, illness narratives attains this crucial role because they can be seen an effort of those who are afflicted by disease to ‘construct new maps and new perceptions of their relationship with the world’ (Frank, 1995: 3). Consequently, these narrations have both a personal and a social side to them. They are personal in so much as it is through these narratives that an

effort to regain control and achieve understanding about one's situation arises. Accordingly, and following Frank's argument about the importance of illness narratives in the formation of the way individuals experience being ill, the kind of everyday experiences of Huntington's disease that the participants of my study told me about in the interviews are not an example of a "primary experience" of the disease. Instead, the ethnographic material that I base this thesis upon should be seen as perceptions, meanings and understanding, which have been formed through the construction of the illness narratives by the affected individuals. In other words, the empirical material of this thesis does not provide an "objective" view of everyday life with Huntington's disease, but rather how my participants experience their everyday life, as these experiences are constructed by the way of their illness narratives. Narratives of different kinds are indeed subjective stories, but these stories contains features that are both existential and productive, they are constructions that are used by people, and through these stories we can obtain knowledge about the individual and the society that surrounds this individual (Lundin, 1992: 23). Therefore, and especially if we consider the crucial role of the narrative in the actual formation of the experience itself, I believe that the use of illness narratives offers a very good option for the kind of investigation that I take on in the thesis.

Yet, the general aim of the thesis also raises a question that needs to be discussed in detail. This question concerns the social side of these narratives, and whether these narratives mirror the socio-cultural context in which these stories are formed. Habermas considers that narratives have such features. Narration can be seen as a form of speech that describes 'sociocultural events and objects'. This is based upon the 'everyday world or lifeworld' of the individuals who create these coherent scenarios and articulate shared meanings through narratives (Habermas, 1987: 136). Charlotte Aull Davies makes a similar point in relation to ethnographic interviews and to what these might yield in terms of the general socio-cultural context. A traditional assumption about the ethnographic interview, according to Davies, is that the reports given by the respondents can give access to knowledge about social and cultural realities. The knowledge provided by the interview is thus not only something that has to be seen solely as a consequence of the actual interaction between researcher and respondent. It is an epistemological position suggesting that the only knowledge accessible via interviewing is knowledge about the interview itself; that is, about the basis on which the interviewer and interviewee construct their interaction (Aull Davies, 2008: 107, 109). Relative to these epistemological positions, Aull Davies chooses a position that incorporates aspects from both camps. She argues that while the interviews cannot be

seen as a straightforward mirror of a collective cultural and social level, there is nevertheless a connection or interdependency between the micro and macro level that comes forward in the interview. This interdependency allows access to a cultural and social world beyond the individual context of the actual interview (Aull Davies, 2008: 109). One way to achieve such access is of course to interpret and analyse the material obtained in the interviews with the help of cultural and social theories; in my case, the material to be analysed consists of the illness narratives of the participants.

Following Paul Ricoeur's argument on the various positions that a researcher can adopt in relation to interpretations of the empirical material, my efforts to analyse the linkage between everyday life with a genetic disease and fundamental patterns of modernity involves a displacement of the illness narratives (Ricoeur, 1981: 34). Parts of this displacement occur in relation to the various steps of reconstruction (see section 7.2) that forms an essential part of ethnography and qualitative methods. Another part of this displacement involves the employment of theoretical perspectives through which my empirical material is contextualized and explained. Such a displacement sets these illness narratives into a different context. This use of an outside theoretical framework, in my case the perspective offered by Habermas, constitutes what Ricoeur has defined as an interpretation that in its nature is a suspicious interpretation, aimed towards disclosing aspects within our lived existence that are hidden from our view (Ricoeur, 1981: 34; Smith, Flowers and Larkin 2009: 36). Therefore, my research also constitutes a certain degree of challenge of the experiences of Huntington's disease expressed by the participants through their illness narratives. Following Smith, Flowers and Larkin, I intend to adopt a middle position in the thesis. The purpose is to incorporate the perspectives of the participants and to attain an outside position through the theoretical framework presented and discussed in the previous chapter (Smith, Flowers and Larkin, 2009: 36). In order to investigate the relation between everyday life with a genetic disease and intrinsic patterns of modernity, I see it as necessary to adopt a position whereby the illness narratives of the participants become contextualized and interpreted in terms of a theoretical framework derived from cultural and social theory. The question concerning the cultural status of the narratives is important, not least for the participants themselves. It originates from the differentiation between lifeworld and system. This can only be made visible if these narrations are contextualized through theory, using the kind of framework that I outlined in the previous chapter.

7.2.2 Limitations of the thesis

This thesis does of course have a number of limitations that have to be acknowledged and discussed. The first, and maybe most important of these limitations, arises in relation to the number of, and the composition of the group of participants. As I mentioned in my discussion of the recruitment process, the number and composition of the group of participants was highly dependent on those who came forward as a result of my personal visits and advertisements. This process of recruitment therefore meant that I did not choose to steer or control the composition of my participants as to how these individuals were affected by Huntington's disease. As things turned out, the participants came to represent a cross-section of the various ways an individual can be affected by the disease, ranging from being at risk to being a sufferer. However, it has to be acknowledged that there is predominance among the participants of family members and individuals who have found out that they do not carry the mutated gene that causes the disease. Consequently, the substance of the illness narratives, the various issues that were raised in the interviews, can be seen as dependent on the group of participants. A different combination of participants might have resulted in narratives that contained diverging issues and themes, which subsequently would have affected the content of the thesis.

There is however another side to this discussion that I would like to point out, a side that in my view comes forward in relation to the use of theories in research such as ethnology and other disciplines that employ qualitative methods. Here, anthropologist Clifford Geertz has pointed out that theory acts as a balance between:

> 'Setting down the meaning particular social actions have for the actors whose actions they are, and stating, as explicitly as we can manage, what the knowledge thus attained demonstrates about the society in which it is found and, beyond that, about social life in general' (Geertz, 1973: 27).

The aim of cultural analysis is, Geertz continues, 'to draw large conclusions from small but very densely textured facts; to support broad assertions

about the role of culture in the construction of collective life by engaging them exactly with complex specifics' (Geertz, 1973: 27-28). Following this argument of Geertz', thus contained within ethnology and other interpretative sciences there is an aspect of generalization, of reaching beyond the immediate context that can be found within a small ethnographic sample.

One way to reach beyond the immediate context of the ethnographic material is through theory, by employing cultural and social theory that links the immediate context contained within the ethnographic material with theoretical frameworks such as Habermas' broad theory employed in this thesis. Despite the limitations that are basically adhered to this study, specifically the small number of participants that might affect the substance of the empirical material, this thesis contains a generalizing feature with regard to its claim to knowledge. This generalizing feature comes from the use of cultural and social theory. Our hope and intentions as ethnographers is not only to present knowledge about the immediate context of our ethnographic field. In line with Geertz reasoning above, we also want the results of ethnographic research to demonstrate something about the culture and society in which this ethnographic field is situated, on which this field depends and with which it interacts. Such a generalizing feature of ethnographic research will subsequently enable me to, not only say something about the immediate context of Huntington's disease, but also about the interaction between culture, society and genetic science, as well as modernity in general.

In the next chapter, I will present and discuss the four articles of the thesis.

8. Presentations and discussion of the articles

A presentation of each article will be provided in this chapter, but also a discussion of how the individual articles are related to each other. With regard to the aims and research questions stated in chapter two, these will be addressed in the last and concluding chapter.

8.1 Article I: Drinking Glasses, Doorsteps and Table Edges -The material dimension of experiencing a genetic hazard

Early on in the fieldwork, I noticed that various household objects seemed to attain an important role in the participants' narratives about their experiences of the disease. These household objects became salient in the everyday life of the participants in conjunction with various mishaps. A dropped cup or drinking glass, a stumble on a doorstep, or a bump into a table edge aroused anxiety and fear among the participants. This material dimension seemed to be especially salient for those who were at risk and for those individuals who had gone through predictive genetic testing for Huntington's disease. The setting for this first article is the difficult and uncertain situation of being at risk or having gone through predictive genetic testing for Huntington's disease. At this point in time, the mutated gene has usually not given rise to clear signs and symptoms, such as those neurological symptoms that come at a later stage of the disease. I came to think that this material dimension, especially considering its saliency among those individuals whom I met, was one important dimension of the

way these individuals experienced being at risk or going through predictive genetic testing for the disease. Furthermore, this material dimension was something that has not been investigated in previous research on Huntington's disease. This circumstance also prompted me to make these experiences become the focus for one of the four articles in the thesis.

As to the content of my analysis, I regard these household objects as an example of what Sherry Turkle (Turkle, 2007) has termed as evocative objects; material objects that stand in a direct relationship with our emotional and intellectual being. These evocative objects stirred anxieties and emotions among the affected individuals, but they also convey an experience of corporeal depth among those who face a genetic hazard like Huntington's disease. This later aspect of this material dimension could be linked to Drew Leder's argument about embodiment, and especially about those parts of our body that he describes as phenomenological null-points (Leder, 1990). These phenomenological null-points constitute parts of our body that we have no direct experience of, such as internal organs and process that are hidden under the surface of the body. This means that our experience of these null-points is limited in comparison to those parts of our body that we can experience first-hand through our senses. Genes can be considered as one example of these phenomenological null-points, hidden from our direct experience deep inside the cells of our body. However, for those who are affected by Huntington's disease, one of these these phenomenological nullpints (the mutated gene) becomes part of their everyday life and of their experience of the disease. And it is through these evocative objects that the mutated gene becomes an part of the participants' lifeworld, as these objects bring forward a highly ambivalent awareness and experience of the mutated gene.

In the article, this ambivalence is understood through Maurice Merleau-Ponty's phenomenological theory of our embodied existence, especially his argument about a chiasmatic feature of this embodied existence (Merleau-Ponty, 2002, 1968). On the one hand, the body can be seen as an object with corporeal depth that contains genes. This is the kind of perspective that is endorsed and mediated by science, since its focus is directed upon the mechanistic aspects of our body, as well as the various mechanisms behind the diseases that affect our bodies. On the other hand, this is a body that is also an intentional and lived body prone to become absent in the midst of our daily lives. This is the kind of simultaneous but nevertheless distinct experience of the body that gives rise to ambivalent experiences among the participants.

This article points out the complexity that arises in relation to genetics, and the way individuals who become affected by genetic diseases experience these elusive and abstract parts of our bodies. There is indeed quite a profound difference between those statistical laws that describe the transmission of the mutated gene causing the disease and the way those who in various ways are affected by the disease experience their own bodies in relation to genetics. One aspect of this complexity is the material dimension that I investigate in this article. It is important to understand all those features that are part of this complexity to attain a better knowledge of its entirety. It is of course especially important to achieve a better understanding of the ambivalences that arise in conjunction with the development within genetics, including the increased possibility to perform various sorts of genetic testing on a greater amount of conditions.

8.2 Article II: The Cultural paradox of Predictive Genetic Testing for Huntington's Disease

The aim of the second article is to perform a cultural analysis of the effects and implications of predictive genetic testing for individuals who have undergone such a test for Huntington's disease. The first two articles of the thesis are very much connected, but they also complement each other through this connection. They both show how genetics, when it becomes part of everyday life and everyday experiences, gives rise to ambivalences among the affected individuals. These are ambivalences that occur in connection with the way we experience our own bodies, experiences that are challenged by genetics and the possibilities that come with genetics and genetic testing. In this article, however, the focus is upon how ambivalence among the participants can be understood in terms of a cultural paradox. Here, I investigate the context of the first article from a slightly different point of view, when I investigate predictive genetic testing for Huntington's disease in terms of cultural categorization. This shift in focus means that these two articles operate on a slightly different analytical level. Whereas the analysis of the first article has a focus upon embodiment and the experience of the body, this article shifts the focus to how the situation that we encountered in the previous article can be understood in terms of cultural categorization and a cultural paradox. I consider that this shift in focus between the first two articles acknowledges the complexity that exists

in relation to the situation faced by the participants. The different approaches of the articles have enabled me to address this complexity.

In this second article, I use the American anthropologist Victor Turner's concept of liminality (Turner, 1977, 1979). This term captures the abstract and elusive character of our genes, which was found to generate a liminal space wherein the affected individuals are situated between normality and abnormality. To be situated within this liminal space gives rise to intuitions, emotions and actions among the affected individuals; this includes fluctuation between the present and an anticipated future in their everyday life. From a cultural perspective, these responses and actions of the affected individuals are seen as a result of a cultural paradox that arises from a juxtaposition of normality and abnormality within this liminal space. Undergoing predictive genetic testing does not appear to resolve this situation. Despite the knowledge of their genetic status, revealed through the predictive genetic test, the affected individuals are still situated within this liminal space with its juxtaposition of normality and abnormality. As a consequence of this juxtaposition, the boundaries that separate the categories of being at risk for Huntington's disease, being a pre-symptomatic gene carrier or being symptomatic and afflicted with the disease are dissolved in the everyday life of the affected individuals. This sort of juxtaposition of cultural classifications constitutes a cultural paradox that might create disagreement in the relations between medical expertise and lay people as genetics and genomics is put to use within mainstream health-care. As the possibilities of making various disease predictions on the basis of genetic and genomic knowledge expand, the sort of cultural paradox that is investigated in this article might apply to a far greater number of individuals than those who are affected by Huntington's disease. In relation to this expansion of our ability to make medical predictions on the basis of genetics, certain issues arise. The proclaimed right of those who are situated within this liminal space to define the boundaries of normality and abnormality raises questions regarding the relationship between lay people, medical expertise and the health-care system.

8.3 Article III: A Molecular Body in a Digital Society

The third article of the thesis is about one way of handling the ambivalent experiences that was investigated in the previous two articles. In the article, I investigate the role of the Internet and the social media in generating social formations and identities in relation to genetics. Huntington's disease

is a rare disease, which means that the number of individuals with whom an affected individual can share his/her experiences might be limited. As I mentioned in previous chapters, I followed a local support group for some time during my fieldwork. Relatives of afflicted individuals met regularly in order to support each other. Some of the participants talked about how social media (Facebook) had attained a similar role as the support group that I was following. The similarities and differences between these two ways for the affected individuals to organize themselves intrigued me. As mentioned in the chapter presenting previous research, the growing importance of patient organizations in medical research has been acknowledged and investigated by cultural and social researchers. However, much of this research has not specifically been investigating the role of Internet, and especially not the role of social media. My ethnographic material covered face-to-face interactions, within the local support group that I followed. It also consisted of material relating to Facebook. In view of this, I saw a possibility to investigate the role of Internet and new social media.

Analysis of the ethnographic material indicates that one of the primary roles of the Internet and Facebook could be connected to the specific spatiality of the Internet. In the article, I analyse Facebook as an example of a rhizomic social space (Deleuze and Guattari, 2004; Lefebvre, 1991) where online networks of interactions can take place among individuals affected by Huntington's disease. Drawing upon Paul Rabinow's concept of biosociality that describes how new knowledge within genetics and biomedicine gives rise to new social formations (Hagen, 2012; Rabinow, 1996), these networked interactions are seen in terms of an online biosociality that grew up outside more formal organizations as a form of grass-root movement. Being part of this online biosociality enables affected individuals to form a large number of online friends with whom they can communicate on issues related to various aspects of a disease, for example the experience of suffering from Huntington's disease despite having no neurological symptoms. Moreover, the ethnographic material also indicated that this online bio-sociality also enabled certain individuals to construct a new identity, HD+. This amounted to a layman's alternative to the current diagnostic criteria for Huntington's disease. Thus through its spatial features, the Internet presents novel opportunities to come together in various sorts of online communities. Not only do these benefit individuals with rare genetic diseases, but also those with common ailments. In the context of Huntington's disease, new disease identities have been formed among affected individuals, which includes an alternative understanding of the current diagnostic criteria employed within the health-care system.

In relation to the previous two articles in the thesis, this article investigates how the specific spatiality of the Internet enables some of whom I met during my fieldwork to establish a large amount of contacts with individuals who were in a similar situation. These contacts were important in order to handle the ambivalence that was investigated in the first articles of the thesis. The HD+ identity, formed in part on the basis of Facebook communication, can be seen as a response to the ambivalences that arise when you are at risk for Huntington's disease, or when you have gone through predictive genetic testing.

8.4 Article IV: For Better or for Worse – Lifeworld, system and family caregiving for a chronic genetic disease

The fourth and last article performs a cultural analysis of the meeting between families involved in caregiving in cases of Huntington's disease and the welfare system. Whereas the first three articles in various ways revolve around the first phases of the disease, this article investigates an aspect of the disease that arises when the mutated gene gives rise to neurological symptoms, which put the afflicted individual and the family in need of assistance. The interaction between the affected families and the welfare system was in fact one of the most prominent themes in the narratives. It was a subject that quickly caught my attention as I performed my interviews. When I started my fieldwork I was quite influenced by research that was inspired by Michel Foucault and his notion of power and the exercise of power within the modern society. However, as I encountered the topic of the welfare state within the narratives of the affected individuals, the system-like aspects of the welfare state came forward as an important key to the experiences that the families told me about in the interviews. Such a system-like character of the welfare state led me to analyse this feature of Huntington's disease, the family caregiving, in terms of a difference between the lifeworld of the affected families and instrumental rationality employed by the welfare system.

The cultural analysis that I performed in this article shows that the interaction between the affected families and the welfare system is concentrated around differences between the action of the affected families

and the action that guided the welfare system (Habermas, 1987). The affected families' understanding about the caregiving arose as a consequence of communicative action, whereas the actions of the welfare system were shaped by an instrumental legal discourse used in order to allocate resources within the society. Compared with other studies, performed for example within the medical sciences, this study exemplifies how central features of modernity form a crucial part in the shaping of how families involved in family caregiving experience the interaction with the welfare system.

However, the article also shows how families involved in caregiving are able to overcome and reduce the dominance attained by the system. This occurs through a 'Third space' (Bhabha, 1994) that is characterized as a hybrid form of action, as an amalgamation of communicative and instrumental action. The last part of the article has exemplified this aspect in the context of a local patient support group, whose activities constitute a movement between their own illness stories and the legal discourse used by the system. In this context, an empowering 'Third space' gives them the opportunity to act in a more instrumental manner towards the system. The emergence of this hybrid is linked with the cultural and social process of modernization and the separation between lifeworld and system. This shows how new forms of empowerment arise from these aspects of modernity. The investigation therefore points towards how the division between communicative and instrumental action constitutes, not an end-point in regard to cultural processes within modernity, but rather a point of departure from which hybrid forms of communications and action arise. As such, these hybrid forms represent an important cultural phenomenon to consider in our attempts to understand cultural and social change within modernity.

This article has been co-authored with three other scholars (Susanne Lundin and Tom O'Dell, both at the Department of Arts and Cultural Science at Lund University, and Åsa Petersén at the Department for Experimental Medical Science at Lund University). This co-authorship arose as a consequence of the interdisciplinary research environment (the Bagadilico consortium) wherein this Ph.D.-project was conducted. The three scholars have also functioned as my supervisor (Lundin) and assistant supervisors (O'Dell and Petersén) during the Ph.D.-project, a composition that reflects the interdisciplinary approach of the project and the Bagadilico consortium as a whole. In order to achieve a close collaboration that transcended established boundaries between disciplines, the decision was made to let one of the articles within the thesis be co-authored by Hagen, Lundin, O'Dell and Petersén. To let this interdisciplinary collaboration revolve

around a co-authored article was seen as the best way to engage in a constructive and productive discussion. A co-authorship between the involved parties enabled the authors to a deeper discussion and subsequent understanding of similarities and differences that exist between ethnology and medicine in relation to theoretical and methodological aspects.

The division of labour in relation to the article is as follows.

The empirical material of the article was in its entirety obtained, transcribed and analysed by myself. The main theoretical framework of the article, which is based on Jürgen Habermas' lifeworld and system perspective, was my contribution; in the initial drafts of the article, this theoretical framework was paired with the empirical material. Lundin commented upon these earlier drafts; in conjunction with these comments, Lundin pointed out the importance of Arthur Frank's perspective as a potential source in order to overcome initial difficulties with the article. I reworked the earlier drafts of the article, adding the theoretical combination of Habermas and Frank's perspectives, in which illness narratives are seen as an example of communicative action. Petersén provided the relevant references for the section that presents Huntington's disease; these references were mainly from medical review articles. Key articles within the medical research on Huntington's disease were also provided by Petersén, for example the article that reported about the finding of the mutated gene in 1993 (Huntington's disease collaborative research group, 1993). O'Dell's contribution came at later stage in the work, mainly concerned with the later parts of the article. In these later parts of the article, a post-colonial perspective is used in order to understand and explain exchanges between lifeworld and system. This perspective provided a new approach to the existing argument. O'Dell pointed out the relevance of this post-colonial aspect by commenting on the existing text, giving advice about relevant literature. He also made suggestions explicit by complementing the written text with written passages that cited Homi K. Bhabha (Bhabha, 1994) and Robert Young (Young, 1995) (these passages can be found on p. 551 in the published version of the article. The later parts of the article commence on p. 550-553. See original article). As a consequence of O'Dell's comments and written suggestions, I read the suggested literature and rewrote the written suggestions made by O'Dell, as well as augmenting these suggestions with the existing argument.

9. Concluding Thoughts: Body, Rationality, and Ambivalence

In this concluding chapter of the thesis, I intend to address the research questions by combining the findings of the four individual articles with the theoretical framework that I discussed in chapter six. I will divide this last chapter into three subsections. I will begin the chapter with a discussion about how genetics can be understood in terms of a system, in this case as an experimental system in which an instrumental and rational approach towards nature made way for the scientific success of genetics. In the second section of the chapter, I will discuss in what way genetics becomes a challenge towards the body, and how this challenge can be understood as part of intrinsic patterns of modernity. In the third section, I will discuss the notion and implications of what I, in chapter six, described as a "Third space". This concept became relevant in conjunction with critique about the sharp and dichotomous nature of modernity that Habermas emphasised in his theoretical framework. In the last section, I will employ this concept when I investigate how the relationship between lifeworld and system give rise to negotiations and empowerment among the affected individuals. These findings are then related to a more general engagement among patients in biomedical research, an argument that also provides a slightly revised picture of previous understanding about the confrontational nature between the lifeworld and the system. I will end the chapter with a more general conclusion.

9.1 Genetics as an experimental system

The most famous figure within genetics is, arguably, Gregor Johann Mendel, the abbot of the Augustine monastery in the town of Brno. During his time in the monastery, Mendel performed a number of experiments on

peas, the result of which he accounted for in two scientific presentations and a scientific thesis. However, his thesis, published in 1866, did not attract any attention, and Mendel went on to pursue other scientific interests that did not concern heredity. The breakthrough came 34 years later, in 1900. Scientists working within different fields of inquiry came to recognise that the results of their experiments, performed on various species, followed those laws for biological inheritance that Mendel had formulated on the basis of his experiments on peas (Bengtsson, 1999: 106). Following the rediscovery of Mendel's thesis, an intensive period of heredity research on both plants and animals was initiated. However, it was not until 1906 that the term "genetics" was coined by the English scientist William Bateson, and we have to wait until 1909 in order for the term "gene" to enter the scientific vocabulary (Müller-Wille and Rheinberger, 2012: 128).

At this time, the work of most biologists was descriptive and speculative, whereas the work of Mendel adhered to an overtly experimental, analytic and quantitative approach to the study of nature and heredity. As the American historian Daniel Kevles points out, while most biologists of the later part of the nineteenth century dealt with organisms on the basis of holistic perspectives in relation to their function, Mendel's work and approach was more like a physicist's or a chemist's way of working. He reduced the organism to a set of deterministic, hereditary elements (Kevles, 1995: 42). By this experimental approach, Mendel was able to manipulate his plants at precisely defined, albeit invisible, points within their overall organization, all the way from their visible appearance to the cellular level (Müller-Wille, 2007, 799). In the late nineteenth century, this methodical approach were endorsed by a wider circle of biologists, who initiated and embarked on research programmes that were focused on a production of scientific knowledge through controlled experimentation. They used plant and animal hybrids, as well as artificial pure lines of various plant species in their experiments. One of the most prominent adherents to this experimental approach was the Danish plant physiologist Wilhelm Johannsen, who formulated the crucial distinction between genotype and phenotype in 1909 (Roll-Hansen, 1978). This distinction conceptualizes the separation between the visible and external features of the organism (the phenotype), and the invisible features that can be found within the genetic make-up of the organism (the genotype) (Griffiths et. al., 2000). The genotype of the organism came to be seen as a feature within the organism that was predictable and stable, independent of all the contingencies that were brought upon the organism from the environment and its life-history.

I consider that the birth of genetics as a scientific discipline also implied the birth of an experimental system. Many of the crucial discoveries of genetics were made by using a number of model organisms that were manipulated in order to study what could not be seen by the naked eye. As noted by the German sociologist and Italian molecular biologist Helga Nowotny and Giuseppe Testa, one of the main characteristics of the scientific development within genetics and the rest of the life sciences is 'that they make things visible that could not previously be seen' (Nowotny and Testa, 2010: 1). Today, there are of course a number of technical devices to visualize genes and other parts of our body, which are not visible for our naked eye. For the early geneticists, however, various sorts of model organisms became crucial in order for them to overcome the sort of epistemological obstacles that were posed by the presence of hereditary material deep inside within the organism. As pointed out by Gaston Bachelard, science conjures up a world, often by amplifying what is beyond appearance, not by means of magic immanent in reality 'but of rational impulse immanent in mind' (Bachelard, 1984: 13). The use of these manipulated model organisms became a way to investigate what lies beyond the visual appearance of the organism. Such a rational and instrumental scientific strategy was applied in order to overcome the sort of epistemological obstacle that faced these early geneticists. The birth of genetics can thus be seen as a result of a decidedly goal-oriented approach, which was not based on a study of nature as it appeared for the naked eye, but rather on manipulated parts of nature as a way to achieve experimental control and reduction. The formulation of such important concepts as gene, genotype and phenotype, still very much valid in today's life sciences, was made on the basis of knowledge produced through this rational and instrumental approach towards nature (Müller-Wille and Rheinberger, 2012: 127-160).

In the interwar period, and especially after the Second World War, molecular biology entered the scientific arena as a new and powerful force (Kay, 1993: 3). Evelyn Fox Keller states that molecular biology sought to reduce the biological world, to 'find the essence of life in organisms so rudimentary and so simple as to be immune from the mystifying and recalcitrant chaos of higher organisms' (Fox Keller, 1995: 81). This ethos was described by the French molecular biologist Jacques Monod as 'what is true for a bacteria is also true for an elephant' (Kay, 1993: 5). One of the main fields of inquiry for this new force in science became the molecular basis of heredity, a task that arguably was crowned by the discovery in 1953 of the structure of the DNA molecule. In many ways though, the reliance upon various model organisms as a way to produce scientific

knowledge, an central strategy already for Mendel, continued to be a basic approach used by natural and medical scientists who worked within molecular biology. With the discovery of DNA and its molecular structure, the gene had been given a material and chemical representation, but its function as an'invisible placeholder for a visible effect' (Müller-Wille and Rheinberger, 2012: 184) was gradually replaced with another sort of representation. In the wake of the important discoveries mentioned above, heredity was no longer seen in terms of a transmission of bodily characters, but of information; the genes containing instructions (Kay, 2000; Fox Keller, 1995: 94-95). Staffan Müller-Wille and Hans-Jörg Rheinberger consider that twentieth-century genetics colligated around these two representations: of genes as a form of atoms around which much of heredity became focused and of these genes as carriers of information. Both of these representations were intertwined with various sorts of experimental technologies; or rather, as Müller-Wille and Rheinberger point out, 'they were materialized by these experimental technologies and thus became efficacious' (Müller-Wille and Rheinberger, 2012: 217).

As an experimental system, genetics has produced extensive and far-reaching knowledge of heredity; this has yielded new and important understanding about our own body, as well as about ourselves as biological organisms. However, the scientific success of this experimental system rests upon its ability to overcome the difficulties of obtaining knowledge about entities and processes taking place deep inside the corporeal depth of the organism. In my view, the way genetics has overcome this epistemological obstacle can be seen as a prime example of the sort of instrumental rationality that characterises the system. Yet, it is also my opinion that this scientific success of genetics carries a great challenge towards the way we experience our bodies in everyday life. In order to gain a deeper understanding of this challenge, I will in the next section of this chapter show how each of the four individual articles are concerned with the framework of lifeworld and system, which I presented in chapter five.

9.2 Genetics as a challenge towards the body

In the first article of the thesis, the challenge is displayed in relation to the role played by various household objects in the everyday life of the participants (Hagen, submitted manuscript). Very much in the same way as I attained an awareness of the presence of genes within my own body, through a perceived physical resemblance between myself and my

biological father, these household objects mediate a similar awareness among the participants that I interviewed. Yet, the article also shows how this awareness is filled with ambivalence as to the exact nature of the awareness that the participants attain through these household objects. In chapter five, I used Drew Leder's argument as one way to describe a lifeworld perspective of the body. Leder characterizes the natural attitude in terms of a dialectics in which our body is both present and absent in our daily life (Leder, 1990). Still, when it comes to those invisible parts of our body that are located deep within our corporeal depths, this dialectics between presence and absence is very much replaced by an absence, since we often do not have any direct experience of the internal features of our body. In relation to these internal features of our body, we encounter what Leder calls phenomenological nullpoints, of which we have no direct experience (Leder. 1990: 43). This absence is valid for the molecular level that comes into focus in connection with such genetic diseases as Huntington's disease. The gene that causes Huntington's disease can therefore be seen as a phenomenological nullpoint. For the participants, like the rest of us, genes are a part of our bodies of which we have no direct sensory experience, apart from the knowledge that we are given through the scientific and medical accounts about genes and genetics. Yet, for those who are faced with Huntington's disease, these phenomenological nullpoints become part of everyday life, which means that there is a divergence between the knowledge about the mutated Huntington gene given through science and the lived experience of genes as part of their bodies.

This divergence between scientific knowledge and lived experience of genes is the point of departure for the first article. Here, the circumstance is investigated of how various household objects, as a consequence of the danger posed by the hazardous Huntington gene, suddenly become evocative objects, through which this gene becomes part of the participants' lifeworld. These objects bring forward an embodied awareness of this phenomenological nullpoint (the mutated Huntington gene) as a potential or actual part of their bodies. However, because this embodied awareness concerns such an abstract and elusive part of the body, it becomes an awareness that contains much ambivalence. I am not implying that the origin of this ambivalence is a result of a lack of understanding of genetics or information about genetics on behalf of the affected individuals. In many cases, these individuals have an extensive understanding of genetics. Instead, I trace the origin for this ambivalence to the way genetics and genetic knowledge concerns itself with parts of the body that are not readily included in our pre-scientific and self-evident "setting", our lifeworld, in

the same way as all those features of our body that we have a more direct experience of through our senses.

Ambivalence is also a prominent feature of the second article, which focuses on the predictive genetic testing for Huntington's disease (Hagen, 2013). As I have shown in the previous section of this chapter, the scientific production of genetic knowledge has been founded on the employment of instrumental rationality ever since the birth of genetics as a scientific discipline. In fact, as I discussed in the previous section, genetics can be seen as an experimental system; in the case of Huntington's disease, this has provided vital and important knowledge about the disease, including the possibility to detect the presence of the mutation that causes the disease through predictive genetic testing. The cultural analysis performed in the second article shows how the affected individuals become situated in liminal space, which triggers an everyday situation filled with ambiguity about their genetic status, as well as their present and future health. The possibility of performing this kind of genetic testing, of detecting and predicting the onset of disease before visual signs and symptoms of the disease are present, does not only create ambivalent feelings among the affected individuals. It also influences the cultural level, when recognised cultural categories are dissolved as a consequence of this possibility of predicting future disease before the onset of visible signs and symptoms.

I consider both these articles to be centred on the relationship between lifeworld and system. On the one hand, we have the pre-scientific and self-evident setting of the "lifeworld body", in which our genes are featured as phenomenological nullpoints. On the other hand, we have an experimental system that produces scientific and medical knowledge about these parts of our body. The first two articles of the thesis show this pre-scientific and self-evident "setting" of the lifeworld to be challenged by genetics and genetic knowledge. In this way, genetics can be seen as form of challenge to the body, a challenge that gives rise to ambivalent experiences among those who are affected by the disease. The social employment of instrumental rationality in the form of systems has indeed brought both progress and advantages for society; scientific discoveries such as those produced by genetics, are indeed crucial both for the affected individuals and for society, since these discoveries offer means for a potential cure for Huntington's disease. Yet, this appliance of instrumental rationality within the context of biology and medicine has also brought forward the sort of differentiation, along with a subsequent ambivalence, between lifeworld and system that constitutes a cultural pattern of modernity.

The third article can also be seen through the lifeworld and system perspective, as a way to handle the sort of ambivalence that I discussed above. Here, Internet and social media turn out to be one source through which the affected individuals can obtain support from others who are affected by Huntington's disease (Hagen, 2012). But, the article also shows how the Internet provides the setting for the creation of a disease identity among the affected individuals. This disease identity, which is called HD+, can be seen as a response on the type of challenge towards "lifeworld body" posed by genetics, especially in relation to the kind of cultural paradox that could be seen in conjunction with predictive genetic testing. The question that arise in relation to the kind of predictive genetic testing that can be done on Huntington's disease concerns the issue of when you are to be considered as ill if you are carrying the gene that causes the disease. Currently, the actual diagnosis is established when clear neurological signs and symptoms of the disease are present in the affected individual, but this practice is contested through the HD+ identity as it aims to capture a presence of Huntington's disease despite a non-presence of clear neurological symptoms.

Consequently, the HD+ identity can be seen as form of response towards the ambivalent feelings among the affected individuals, but also as a response towards the challenge that predictive genetic testing poses on the cultural level. As I mentioned above, one consequence of predictive genetic testing for Huntington's disease was that these genetic predictions seemed to give rise to a cultural paradox with regard to cultural categorization (Hagen, 2013; Konrad, 2005). The question of whether you are healthy or suffering from the disease as a gene carrier for Huntington's disease is a difficult issue to handle in the everyday life of those who are unfortunate to be in this situation. It is also complicated on a cultural level, when predictions like these dissolve recognized cultural categories. The HD+ identity that was established through an Internet-based communication becomes a way for the affected individuals to handle and navigate the liminal space, which I investigated in the second article (Hagen, 2013). The point of departure for the topics that I investigate in this article, once again concerns the divergence between genetic knowledge and the lived experience of genetics. As I see it, this is a divergence that arises as a consequence of intrinsic cultural patterns within modernity; the appliance of instrumental rationality of the system, which brings forward a subsequent differentiation from the lifeworld.

The picture that emerges, as a consequence of this cultural pattern of differentiation that I discussed above, is that the lived everyday experience of Huntington's disease is challenged by the instrumental rationality of the

system. This challenge comes from the instrumental rationality employed by experimental system of genetics that has produced new scientific knowledge that confronts the pre-scientific experience of our bodies. The relationship between lifeworld and system can therefore bee seen as a confrontational relationship in which the lifeworld is, as both Habermas and Frank suggests, subjugated by the system (Frank, 1995:5; Habermas, 1987: 332-373). But is this really the case? Are we to view the challenge posed by instrumental rationality as a sort of colonialization of the lifeworld by the system? These questions will be addressed in the next section.

9.3 "Third space" and the relationship between lifeworld and system

As stated by Arthur Frank in conjunction with the cultural status of illness narratives, the modern condition can be seen as a circulation of stories, which are 'professional or lay' but not altogether equal (Frank, 1995: 5). According to Frank, the cultural status of the everyday experience can then be seen as dominated or subjugated, within the modern society. Frank's description of modernity is an appropriate depiction in relation to certain aspects of the welfare system; which is part of the topic for the fourth article in the thesis (Hagen et. al., 2012). This article also shows how the employment of instrumental rationality gives rise to ambivalences among the affected individuals. In this case, however, the challenge does not come from a scientific experimental system, but from the administrative system of the Swedish welfare state. This time the effects of the instrumental rationality of the system are manifested through the legal discourse used by the welfare system in order to allocate resources. In a similar way as with the challenge presented by genetics towards the way we experience our bodies, this legal discourse challenges the perspective of caregiving taken by the affected individuals. Albeit we in this context encounter a different form of system, I consider the ambivalences seen in this situation to arise from the same cultural pattern. Not surprisingly, this cultural pattern of modernity originates from the wide-range structural change of differentiation between lifeworld and system resulting from the emergence of rational thinking, and the subsequent use of instrumental rationality in various contexts within the society.

Even though the system poses a challenge towards the lifeworld, to describe this challenge only in terms of a confrontation is not an entirely

adequate perspective of the relation between everyday life with a genetic disease and cultural patterns of modernity. From a more theoretical viewpoint, this latter aspect then links up with those perspectives that question the sort of sharp division between lifeworld and system suggested by Habermas. These are the perspectives that I discussed in chapter five emphasising the "Third" as an alternative to dichotomous perspectives. This matter is examined in article number four, where my co-authors and I use Homi K. Bhabha's "Third space" concept as a way to capture the relationship between lifeworld and system (Hagen et. al, 2012; Bhabha, 1994). This "Third space" is to be seen as a hybrid form of action that incorporates perspectives from both the lifeworld and the system. In the article about family caregiving for Huntington's disease, this sort of hybrid form of action enabled the affected families to act towards the welfare system by combining their own perspectives on the caregiving situation with the instrumental rationality used by the system.

Within the context of family caregiving for Huntington's disease, the appliance of instrumental rationality consisted of a legal discourse used by the system in order to allocate the sort of resources that the affected families were in need of. However, despite feelings of frustration and anger when the evaluations made by the system did not align with the affected families' understanding of their needs, this did not cause a stalemate between the families and the system as might be expected. Instead, an interesting process could be seen taking place within what we have defined as a "Third space", a process that incorporated both lifeworld and the system in a hybrid form of action. In the case of family caregiving for Huntington's disease, this hybrid form of action meant that the affected families did not discard the legal discourse of the welfare system. Rather, it was taken up to be used as a strategy to communicate with and influence the welfare system. In my view, we can see a similar situation in relation to the scientific system, which has resulted in an active involvement of patients in biomedical research and medical practice (e.g Gibbon and Novas 2008). The establishment of a "Third space" has meant that patient organizations of different sizes and in different contexts, both national and in relation to different diseases have become important actors with regard to decision-making in scientific and technical issues. A further result is that prospects for democratic participation have been opened up, leading to new forms of relations between science and society (Rabeharisoa and Callon, 2006).

These features can be exemplified in relation to the AIDS-activism in San Francisco during the 1980s, where the gay-movement was able to influence and eventually be part of the design and practice of clinical studies on HIV.

The gay-movement was able to attain this kind of position, not only through acting on behalf of their lived experience and political influence, but more so through in-depth knowledge of medicine and the scientific design of clinical studies. In other words, their activism made use of the hybrid nature of the problem that they were facing in the wake of an increasing AIDS epidemic. This hybridity consisted both of their own illness narratives, but also of a medical and scientific narrative that guided the design and practice of vital clinical studies on the AIDS epidemic (Epstein, 1998). Another, and even more far-reaching example, can be seen within the context of autism, where parents were able to achieve considerable influence on biomedical research through a "Third space" that included both lay-expertise and vital infrastructure related to biomedical research on autism (in the form of a bio-bank founded and run by the parents themselves) (Silverman, 2008). This sort of development can also be seen in conjunction with Huntington's disease. As I mentioned in chapter four, Huntington's disease was one of the first diseases in which a quite extensive engagement by patients in medical research emerged. This was most notable through the work of the Hereditary Disease Foundation, founded by the American psychologist Milton Wexler, taking several initiatives to set up interdisciplinary scientific workshops as a strategy to promote new and innovative research on the disease. Today, the foundation is one of the major financial benefactors within research on Huntington's disease (Wexler, 1995).

These examples show, I believe, a situation that goes somewhat beyond the sort of dichotomous description of modernity that I exemplified above and in previous chapters. Instead of a confrontation that leads into a stalemate between lifeworld and system, we are here encountering a form of action that combines the perspectives of both the lifeworld and system. Moreover, this form of action offers an opportunity for negotiation and empowerment (Ikas and Wagner, 2009:2). As noted by Robert Young, a "Third space" is 'a site of production' (Young, 2009: 82), a site where the sharp distinction between lifeworld and system becomes less sharp and less dichotomous, where new forms of engagements can be established as a consequence of the sort of empowerment and negotiations that characterize these "Third spaces". The growing influence of patient organizations upon biomedical research illustrates this latter aspect. But it also shows how those intrinsic cultural patterns of modernity are influencing, or even shaping, the interaction between genetics and society. One basis for the sort of lay or patient engagement that I have exemplified above can be found in the relationship between lifeworld and system, which are the products of some of the hallmarks of modernity.

In this thesis, I have investigated the linkage between everyday life with Huntington's disease and patterns of modernity. Biology and genetics is of course very much present in the material, but there is also ambivalence contained within the everyday experiences that I encountered in my ethnographic material. Instead of giving rise to emerging biological identities as suggested by for example Nikolas Rose and others (Rose, 2007; Novas and Rose, 2000), genetics and genetic knowledge constituted something that should be regarded in terms of a challenge towards the way we experience our bodies in our everyday life. In my opinion, such a situation can be seen in terms of modernity and its cultural patterns of instrumental rationality and differentiation. These cultural patterns gave rise to a divergence between scientific knowledge and the lived experience, displayed in various ways on the level of everyday life of individuals affected by Huntington's disease. The result of this divergence is an everyday experience of ambivalence. I consider this to be slightly diverging from views in which the impact of new biological knowledge is seen in terms of biological identities based upon findings made within the biomedical sciences. I think these views are too simplistic because they do not address the complexity displayed in the articles that are included in this thesis. Instead, I suggest that at least part of the scientific progress in the biomedical sciences should revolve around the interaction between lifeworld and system. That is, scientific developments within biomedicine will undoubtedly continue to present both results and medical applications that will challenge our "lifeworld experience" of our body. The scientific progress within neuroscience, which offers new perspectives on our brain and on us as humans, is one example of such a challenge. Yet, as I discussed in the later part of this concluding discussion, these challenges of the lifeworld might not take a route of confrontation, but rather bring attention to additional examples of those "Third spaces" that I discussed above. As anthropologists Margaret Lock and Vinh-Kim Nguen point out, the question of 'to what extent individuals may experience themselves as profoundly changed on the basis of knowledge about the genetic self' (Lock and Nguyen, 2010: 304) might not be a question that is to be seen in terms of lifeworld, system or, for that matter, biopower. Instead, it should perhaps be regarded in terms of a combination of all these influential perspectives. These "Third spaces" will then be important sites in which the implications of the scientific development within genetics and the biomedical sciences take shape in society.

10. Svensk sammanfattning

Syftet med föreliggande etnologiska avhandling är att undersöka kopplingen mellan vardagserfarenheter av en genetisk sjukdom och inneboende mönster och mekanismer inom det moderna samhället. Avhandlingen är en sammanläggningsavhandling utförd inom ramen för den tvärvetenskapliga forskningsmiljön Basal Ganglia Disorders Linnaeus Consortium (Bagadilico) vid Lunds universitet. De forskare som är verksamma inom Bagadilico verkar främst inom de medicinska och biomedicinska forskningsdisciplinerna, men miljön består även av forskare verksamma inom det humanistiska ämnesområdet, exempelvis etnologi. Forskningen inom Bagadilico är främst inriktad på Parkinsons och Huntingtons sjukdom och föreliggande avhandling behandlar kulturella och sociala aspekter kring Huntingtons sjukdom.

Huntingtons sjukdom är en genetisk sjukdom som orsakas av en mutation i en gen. Den är en autosomalt dominant sjukdom vilket betyder att det föreligger en 50 % risk att mutationen ärvs från en drabbad individ till dennes barn. Den genetiska mutation som orsakar Huntingtons sjukdom har så kallad 100 % penetrans vilket innebär att en individ som bär på mutationen vid någon tidpunkt i livet kommer att insjukna i Huntingtons sjukdom. Vanligtvis så debuterar sjukdomen i medelåldern med neurologiska symptom vilka främst innefattar svårigheter för den drabbade individen att koordinera och utföra rörelser. Utöver de neurologiska symptomen så kan den drabbade individen också ha olika psykiatriska symptom såsom depression, humörsvängningar och förändringar i personligheten. De psykiatriska symptomen kan föregå debuten av de neurologiska symptomen, ibland upp till tio år och utgör ofta en stor påfrestning för den drabbade och dennes familj. I senare stadier av Huntingtons sjukdom förekommer också olika kognitiva symptom, såsom demens. I nuläget finns det ingen typ av behandling som botar eller stoppar sjukdomsprocessen, däremot finns det behandlingar som lindrar de olika symptom som Huntingtons sjukdom ger upphov till. Sedan början av 1990-talet finns möjligheten för individer som befinner sig i riskzonen för sjukdomen att ta ett prediktivt genetiskt test vilket ger svar på huruvida individen i fråga bär på den muterade gen som orsakar sjukdomen. På

grund av att mutationen har en 100% penetrans så ger alltså det prediktiva testet ett besked om att individen kommer att insjukna i Huntingtons sjukdom, men testet kan inte ge ett besked eller tidpunkt när sjukdomen kommer att debutera.

I samband med avhandlingens tillkomst intervjuades elva individer som på olika sätt är drabbade av Huntingtons sjukdom. Dessa intervjuer var upplagda utifrån målsättningen att dessa individer skulle kunna berätta om sina erfarenheter av Huntingtons sjukdom. Med tillåtelse av de individer som intervjuades så spelades in och transkriberades sedan av författaren till ett manuskript som ordagrant återgav intervjuerna. Dessa manuskript analyserades sedan av författaren och utifrån denna analys kunde ett antal teman urskiljas vilka var gemensamma för de olika intervjuerna. Dessa teman utgjorde sedan grunden för fyra vetenskapliga artiklar som med hjälp av kultur och samhällsvetenskaplig teori analyserade de teman som varje artikel behandlade. Jag ska nedan ge en kort sammanfattning av varje artikel.

Artikel nr. 1: Drinking glasses, doorsteps and table edges – The material dimension of experiencing a genetic hazard (manuskript)

Artikeln undersöker den roll som olika föremål har i samband med att individer befinner sig i risk för Huntingtons sjukdom eller har tagit ett prediktivt genetiskt test för att avgöra huruvida de är bärare av den mutation som orsakar sjukdomen. I intervjuerna som författaren gjorde med individer som befann sig i en sådan situation berättades ofta om hur olika föremål, såsom dricksglas, dörrtrösklar samt bordskanter, fick en speciell betydelse för dessa individer. Ett tappat dricksglas, en tröskel som man snubblar på eller en bordskant som man stöter i utgör ett tecken på att man är bärare av den muterade gen som orsakar sjukdomen eller att sjukdomen är på väg att debutera i form av neurologiska symptom. Artikeln ser dessa föremåls betydelse i skenet av att våra gener utgör en del av vår kropp som vi inte har någon direkt erfarenhet av, på samma sätt som de delar av kroppen som är direkt tillgängliga för våra sinnen. Till skillnad från exempelvis våra fötter och händer så är gener något som återfinns djupt inne i våra kroppar, delar av vår kropp som vi varken kan ta på eller se med hjälp av våra ögon. Vår kunskap om genernas existens och dess betydelse

är en kunskap som framkommit via vetenskapen, framförallt via genetikens framgångar.

För många av oss så blir denna kunskap något som vi inte behöver ta ställning till, genernas existens och betydelse för oss förblir en tämligen abstrakt kunskap som vi inte tvingas förhålla oss till i vår vardag. För de individer som är drabbade av Huntingtons sjukdom så blir dock den gen som orsakar sjukdomen en del av deras vardag. Denna otillgängliga och abstrakta del av deras kroppar blir något som de måste förhålla sig till på grund av den fara som mutationen för med sig. Och det är i anslutning till detta förhållande av abstrakta men farofyllda gener som olika föremål får en betydelse i de drabbade individernas vardag. Att tappa ett dricksglas, snubbla över en tröskel eller att stöta i en bordskant utgör ett tecken på mutationens eller sjukdomens existens. Dessa föremål har en viktig roll i att konkretisera den muterade Huntingtongenen och den fara som denna muterade gen utgör i dessa individers vardag. Den betydelse som dessa olika föremål spelar i de drabbade individernas vardag visar på den komplexitet som finns i relation till genetik och upplevelsen av genetiska sjukdomar.

Artikel nr. 2: The cultural paradox of predictive genetic testing for Huntington's disease. *Ethnologia Europaea* 43(1), 55-67.

Artikeln undersöker upplevelserna hos individer som befinner sig i risk för Huntingtons sjukdom samt upplevelserna i samband med att individer som befinner sig i risk tar ett prediktivt genetiskt test för att få reda på om man är bärare av den muterade gen som orsakar sjukdomen. Emedan den första artikelns etnografiska undersökning fokuserade på vardagens ”mikro-nivå” i samband med undersökningen av föremåls roll och betydelse av vardagserfarenheter av Huntingtons sjukdom, så undersöker denna artikel dessa vardagsupplevelser av sjukdomen med fokus på kulturella kategoriseringar. Artikeln pekar återigen på hur existensen av abstrakta men farofyllda gener i de drabbade individernas vardag ger upphov till en komplexitet, vilken i detta fall berör kulturella kategoriseringar av vad som räknas som friskt och sjukt.

Artikeln visar på hur dessa kulturella kategoriseringar löses upp i samband med att man befinner sig i risk för Huntingtons sjukdom eller har tagit ett prediktivt test för sjukdomen. De individer som befinner sig i riskzonen för sjukdomen berättar om erfarenheter som beskriver en situation av att befinna sig i ett ”mellanrum” mellan att vara frisk eller sjuk. Att vara i

riskzonen att ärva den mutation som orsakar sjukdomen innebär en situation då man är varken frisk eller sjuk, en situation som är både svår och pressad då man inte har några kulturella verktyg, i form av klara kategoriseringar, för att hantera denna situation. Artikeln visar dessutom på att åtgärden att ta ett prediktivt genetiskt test för att få kunskap kring sin faktiska genetiska status inte helt löser denna situation. Förvisso ger testet ett svar på huruvida en individ bär på den mutation som orsakar Huntingtons sjukdom, men denna information utgör likväl en kunskap som initialt kan vara svår att ta till sig för de drabbade individerna. Detta innebär inte att de drabbade individerna inte förstår den information som delges via det prediktiva genetiska testet, utan snarare att det föreligger en diskrepans mellan den information som delges via det genetiska testet och de upplevelser som de drabbade har i sin vardag. För dem som inte befinns vara bärare av den muterade Huntingtongenen så kan det initialt vara svårt att ta till sig att ens kropp är fri från mutationen, och man är således fortfarande i tvivelsmål kring huruvida man är frisk eller sjuk. För de individer som befinns vara bärare av mutationen så uppstår frågan om när man kommer att insjukna i Huntingtons sjukdom, när de neurologiska symptom som utgör kriteriet för att räknas som sjuk skall debutera. Den etnografiska undersökningen visar på att de kulturella kategoriseringar som utgör tolkningsverktyg och kulturellt regalerar förhållandet mellan vad som räknas som friskt eller sjukt upplöses i samband med de situationer som de drabbade individerna hamnar i. Denna situation utgör en kulturell paradox på grund av att dessa individer samtidigt är både friska och sjuka, en paradox som kan komma att omfatta fler individer i samhället i samband med att genetiska diagnostiska metoder kan komma att bli ett vanligt inslag i framtidens sjukvård.

Artikel nr. 3: A molecular body in a digital society. I: M. Liljefors, S. Lundin, A. Wiszmeg (red) The *Atomized Body*. Lund: Nordic Academic Press.

Den tredje artikeln undersöker den roll som Internet och sociala medier har för de drabbade individerna. Internet och speciellt sociala medier (Facebook) befanns spela en viktig roll för vissa av de drabbade individerna, framförallt i relation till den situation som beskrevs i avhandlingens andra artikel. En del av de individer som intervjuades skaffade sig stöd och information via en lokal stödgrupp för anhöriga till personer som är sjuka i Huntingtons sjukdom. Via denna stödgrupp kunde man få information, uppmuntran kring olika praktiska saker som man som

anhörig stod inför i sin vardag. Via denna stödgrupp fick man också känslomässigt stöd att hantera en ofta svår och pressad vardag. Internet och sociala medier utgjorde dock ett alternativ till denna stödgrupp för en av de individer som intervjuades, ett alternativ som är intressant med avseende på den utveckling som vi för närvarande ser i relation till en allt ökande digitalisering av vårt samhälle och vårt sätt att kommunicera med varandra.

För individer som på olika sätt är drabbade av en sådan ovanlig sjukdom som Huntingtons sjukdom så erbjuder Internet och sociala medier en möjlighet att få kontakt med ett större antal individer som befinner sig i samma situation. Denna möjlighet uppstår på grund av Internets uppbyggnad vilken ger möjlighet att kommunicera oberoende av både tid och rum. Sociala medier som Facebook möjliggör således en långt större kontaktyta för de drabbade individerna jämfört med de möjligheter som finns via lokala stödgrupper etc. Facebook utgör ett socialt rum för en del av de drabbade individerna i vilket de kunde få stöd och information från andra drabbade, men via den kontaktyta som etablerades via Facebook kunde man också hantera den kulturella paradox som behandlades i föregående artikel. Via de kontakter som etablerades via Facebook kunde en sjukdomsidentitet konstrueras vilken adresserade den situation i vilken de drabbade individerna befann sig i ett ”mellanrum” mellan friskt och sjukt.

De möjligheter till stöd, uppmuntran samt till hantering av en ofta svår och pressad situation som etablerades via Facebook var dessutom intressanta på grund av att kontakterna som skedde via Facebook antog formen av en gräsrotsrörelse. Kontakterna mellan de drabbade individerna upprättades tämligen spontant och utanför sådana kanaler som exempelvis patientorganisationer. Som sådan utgör denna typ av organisering via Internet ett tänkbart alternativ till mera etablerade sätt att organisera sig och skapa kontakt, men vilken effekt ett sådant alternativ kan tänkas ha i relation till patientorganisationer etc är för tidigt att säga.

Artikel nr 4: For better or for worse – Lifeworld, system and family caregiving for a chronic genetic disease. *Culture Unboud* 4.

Den fjärde artikeln undersöker de senare stadierna av Huntingtons sjukdom, de stadier då de neurologiska symptomen har debuterat och då den drabbade familjen ofta måste få hjälp från välfärdsystemet med omhändertagandet av den sjuke. I intervjuerna beskrevs ofta kontakterna med välfärdssystemet som konfliktfyllda. De drabbade individerna

upplevde att de inte fick tillgång till den hjälp som de behövde och kände också frustration i samband med sina kontakter med olika delar av välfärdssystemet. Artikeln analyserar kontakterna mellan de drabbade individerna och välfärdsystemet utifrån en skillnad i betraktelsesätt mellan de drabbade individerna och välfärdssystemet. Emedan de drabbade individernas upplevelse av sin situation och deras behov av hjälp grundläggs i sådana aspekter som närhet, plikt och livshistoria, så grundläggs systemets hantering av deras hjälpbehov i de lagar som reglerar välfärdsystemets allokering av resurser. Lagen utgör det instrument med vilket samhället, på ett rationellt sätt, fördelar den hjälp och de resurser som varje medborgare i staten har rätt till. Det är således två olika perspektiv och synsätt som möts i samband med kontakten mellan de drabbade familjerna och välfärdsystemet; å ena sidan det livsvärldsperspektiv som grundlägger de perspektiv som innehas av de drabbade familjerna, och å andra sidan det perspektiv som innehas av systemet. Välfärdsystemets perspektiv på hjälpsituationen vilken utgår från tolkningar och riktlinjer som har sin grund i lagtexter.

Denna diskrepans mellan livsvärld och system utgör en klassisk problematik inom det moderna samhället, vilken under lång tid har varit föremål för kultur och samhällsvetenskaplig forskning. En del av denna forskning har beskrivit denna diskrepans i termer av en konfrontation eller rent av dominans av det synsätt som karakteriserar systemet. Ett sådant förhållande mellan de drabbade individernas livsvärld och välfärdssystemet kunde till viss del observeras i intervjuerna, men där förekom dessutom exempel på hur familjerna hittade strategier för att kunna kommunicera och skaffa sig egenmakt med hjälp av de instrument som välfärdssystemet använde sig utav för att allokera den hjälp som familjerna var i behov av. Bland annat så utgjorde en lokal stödgrupp en möjlighet för några av de drabbade familjerna till att jämföra erfarenheter och ge varandra praktiska tips för att kunna hantera kontakterna med välfärdssystemet. Vidare så gavs möjligheter via patientorganisationer till att gå kurser i juridik med fokus på de lagar på vilka systemets bedömning av hjälpbehoven vilade på. Relationen mellan livsvärld och system utmärktes alltså inte helt och hållet av en konfrontation, istället så uppnåddes möjligheter till att påverka och förändra sin situation genom att de drabbade familjerna kombinerade sina perspektiv med de perspektiv som innehades av välfärdsystemet.

Dessa fyra artiklar undersöker vardagserfarenheter av Huntingtons sjukdom. I avhandlingens kappa så kopplas dessa vardagserfarenheter till inneboende mönster och mekanismer inom det moderna samhället. Framförallt så kopplas dessa vardagserfarenheter till hur det moderna samhället på många sätt är uppbyggt utifrån en användning av rationellt tänkande inom många områden. Inte minst gäller detta med avseende på vetenskap, vilket i relation till Huntingtons sjukdom kommer till uttryck i samband med de möjligheter som ges via den kunskap som ges via genetikens vetenskapliga utveckling. Denna vetenskapliga utveckling tog sin början under 1900-talets första del och genetiken har sedan dess bidragit med värdefull kunskap om vår genetik genom ett utpräglat instrumentellt rationellt vetenskapligt arbete. Det är också via genetikens vetenskapliga utveckling som möjligheterna till att detektera och diagnosticera Huntingtons sjukdom har blivit möjliga, bland annat genom prediktiv genetisk testning.

Trots de möjligheter som ges via den rationalitet som utmärker genetiken och dess vetenskapliga metod så uppstår en diskrepans mellan hur vi upplever vår kropp i vår vardag och den bild som delges via genetiken. Gener utgör abstrakta och osynliga delar av våra kroppar. Vi har inte samma direkta upplevelser av våra gener som vi exempelvis har av våra händer. Gener ingår inte i den ”förvetenskapliga” kroppsupplevelse som utmärker hur vi upplever kroppen i vår vardag. Genetiken utmanar denna ”förvetenskapliga kroppsupplevelse” i samband med att den ger oss möjligheter till att på olika sätt undersöka våra gener. Det är denna utmaning som utgör den underliggande bakgrunden till flera av avhandlingens artiklar. I avhandlingens första artikel så undersöks hur olika föremål antar en viktig roll i samband med att individer befinner sig i risk för Huntingtons sjukdom. Att tappa ett dricksglas, snubbla över en tröskel eller att stöta i en bordskant utgör ett tecken på mutationens eller sjukdomens existens. Dessa föremål har en viktig roll i att konkretisera den muterade Huntingtongenen och den fara som denna muterade gen utgör i dessa individers vardag. Betydelsen och den roll som dessa föremål spelar i de drabbade individernas vardag speglar den utmaning som genetiken innebär i relation till den kroppsupplevelse som vi har i vår vardag. Denna utmaning utgör också bakgrunden till avhandlingens andra artikel. Artikeln pekar på hur genetik och genetisk kunskap ger upphov till kulturella paradoxer med avseende på hur vi kategoriserar vad som är friskt och sjukt. Genetikens rationella arbetssätt har givit möjligheter till att kunna detektera den muterade Huntingtongenen via prediktiva genetiska test. I likhet med den situation som undersöktes i avhandlingens första artikel så utgör denna möjlighet en utmaning av den ”förvetenskapliga” kroppsupplevelse som

utmärker hur vi upplever kroppen i vår vardag. I samband med att prediktiv genetisk testning ger oss möjligheter till att detektera sjukdomsalstrande gener innan dessa gener ger upphov till tydliga symptom så utmanas dessutom etablerade kulturella ramverk kring förhållandet mellan friskt och sjukt. Denna utmaning måste på olika sätt hanteras av de drabbade individerna, och Internet och sociala medier utgör ett verktyg med hjälp av vilket de drabbade individerna kan komma i kontakt med varandra och hantera den ambivalens som uppstår till följd av den utmaning som beskrivs i avhandlingens två första artiklar.

Den instrumentella rationaliteten utgör också den underliggande bakgrunden till avhandlingens fjärde artikel som undersöker de drabbade familjernas omhändertagande av deras sjuka familjemedlemmar och deras kontakter med välfärdssystemet. I detta sammanhang så tar sig den instrumentella rationaliteten andra uttryck än vad som var fallet med genetikens vetenskapliga arbetssätt. I relation till välfärdssystemets så utgör lagar och andra former av riktlinjer viktiga instrument för att reglera välfärdssystemets funktion i samband med dess allokering av olika resurser till medborgarna. För att kunna fungera på ett tillfredsställande sätt så behöver systemet övergripande riktlinjer, där lagar och andra riktlinjer utgör ytterligare ett exempel på en typ hur ett instrumentellt rationellt arbetssätt utgör en essentiell del i det moderna samhällets uppbyggnad. I likhet med den instrumentella rationalitet som präglar den vetenskapliga metoden så finner vi också i denna kontext uppkomsten av ambivalens i samband med att välfärdssystemets instrumentella rationalitet möter de tankar och perspektiv kring omvårdnadssituationen som de drabbade familjerna har. I likhet med hur genetiken utmanar den ”förvetenskapliga” kroppsupplevelse som utmärker hur vi upplever kroppen i vår vardag, så utmanar välfärdssystems bedömningar av familjernas hjälpbehov det livsvärlds perspektiv som innehas av de drabbade familjerna.

Dessa möten mellan individer som är drabbade av Huntingtons sjukdom och vetenskaplig samt byråkratisk rationalitet utgör en inneboende del i moderniteten och det moderna samhällets uppbyggnad. Förutom den framträdande roll som instrumentellt rationellt tänkande har antagit inom moderniteten, så utgör uppdelningen mellan olika system (vetenskapliga, byråkratiska och ekonomiska) och livsvärld en annan av modernitetens framträdande kulturella drag. Denna uppdelning mellan system och livsvärld kan i sin tur resultera i olika former av ambivalens vilket utgör ett annat utmärkande drag i moderniteten. Ofta har dessa utmärkande drag (instrumentell rationalitet, uppdelning mellan system och livsvärld samt ambivalens) beskrivits i termer av konflikt av kultur och samhällsvetenskaplig forskning. De möten mellan system och livsvärld som

undersöks i avhandlingens fyra artiklar utgör exempel på en inneboende konfliktyta i moderniteten, i vilken system och livsvärld står emot varandra. Avhandlingen nyanserar dock denna bild i den fjärde artikeln som pekar på att uppdelningen mellan system och livsvärld i moderniteten är mindre strikt än vad tidigare forskning ger vid handen. I relation till det byråkratiska välfärdssystemet så visar artikeln på hur systemets och livsvärldens olika perspektiv kombineras med varandra som ett sätt för individer att skaffa sig egenmakt och skapa social förändring. En sådan kombination mellan system och livsvärld ses också i relation till vetenskapen, där olika patientorganisationer har skaffat sig ett större inflytande på genetisk och biomedicinsk forskning genom just att kombinera sina upplevelser som patienter med de synsätt och arbetssätt som omfattas av biomedicinsk forskning. Avhandlingen har således undersökt och identifierat kopplingen mellan vardagserfarenheter av Huntingtons sjukdom och inneboende mönster i det moderna samhället, men pekar dessutom på hur dessa inneboende mönster kan utgöra en grund för förändring och utveckling inom olika delar av samhället.

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Appendix I

Material for recruitment and communication with participants

INFORMATION OCH FÖRFRÅGAN OM DELTAGANDE I ETT ETNOLOGISKT FORSKNINGSPROJEKT KRING ATT LEVA MED HUNTINGTONS SJUKDOM

Hej!

Mitt namn är Niclas Hagen och jag kontaktar dig i ett speciellt ärende. Jag doktorerar i etnologi vid Lunds Universitet och forskar om frågor kring medicin, hälsa och kultur. Jag är verksam inom ett forskningskonsortium (tillhörande Lunds universitet) där det, förutom etnologer, också ingår forskare som arbetar med medicinsk forskning kring Huntingtons sjukdom. I den etnologiska delen av projektet intresserar vi oss för hur individer som på olika sätt drabbats av Huntingtons sjukdom upplever sin livssituation, exempelvis hur sjukdomen påverkar ens vardag, hur man tänker kring sjukdomens ärftlighet, hur man upplever de olika symptomen samt hur dessa upplevelser påverkar och påverkas av de uppfattningar kring Huntingtons som förmedlas av läkare och medicinska forskare. Min forskning syftar till att studera hur framväxten av kunskap kring vår hjärna och dess sjukdomar införlivas i människors vardagsliv och hur denna ”vardagskunskap” samspelar med den medicinska och biologiska kunskap som tas fram inom den medicinska forskningen. Min förhoppning är att kunna studera framväxten av denna ”vardagskunskap”, och dess växelverkan med den medicinska kunskapen, utifrån ett forskningsprojekt där jag kommer att intervjua och följa individer som drabbats av Huntingtons sjukdom. Jag kommer att utföra min forskning i tre viktiga sammanhang där olika typer av ”vardagskunskap” kring Huntingtons sjukdom bildas och på olika sätt samspelar med den medicinska kunskapen: Individen och familjen, patientföreningen och kliniken.

Denna informationsblankett är också en förfrågan till dig om du skulle kunna tänka dig att medverka i detta forskningsprojekt. Som deltagare i projektet kommer jag att vilja intervjua dig om din situation och ditt liv med Huntingtons sjukdom. I intervjun kommer jag att ställa frågor om hur du är drabbad av sjukdomen, dina vardagsrutiner med Huntingtons, hur du ser på ärftlighet och släktskap mot bakgrund av sjukdomen samt hur man som drabbad av Huntingtons tänker kring sådana frågor som identitet och självbild. Vidare kring att träffa andra drabbade inom en patientförening, patientföreningens roll att sprida kunskap om Huntingtons samt frågor kring hur man som drabbad upplever mötet med medicinsk personal

och medicinska undersökningar. Utöver intervjuerna hoppas jag även kunna få träffa och följa dig i delar av din vardag: Att få träffa dig i din hemmiljö, i patientföreningen samt i samband med dina eventuella kontakter med hälso –och sjukvården.

Tid och plats för intervjuerna bestämmer du själv. En intervju kommer att ta 1-3 timmar, och du bestämmer själv vilka frågor som du vill svara på och om du tillåter att intervjun spelas in på band. Du bestämmer givetvis också helt och hållet själv formerna för alla våra kontakter som sker utöver våra intervjuer. Alla våra kontakter och intervjuer sker under tystnadsplikt. *Detta innebär att inget forskningsmaterial som inte är anomyniserat och avidentifierat kommer att spridas.* Din medverkan i projektet är helt fristående från all form av behandlingsverksamhet som sker inom hälso –och sjukvården samt inom den kommunala omsorgsverksamheten. Detta betyder att ditt beslut om medverkan i projektet inte på något sätt kommer att påverka din rätt eller dina möjligheter till behandling som ges inom hälso – och sjukvården eller inom den kommunala omsorgsverksamheten. Ditt eventuella deltagande i projektet är frivilligt och du har rätt att när som helst avbryta allt ditt deltagande i projektet utan särskild förklaring. Allt forskningsmaterial som gäller dig kommer då att förstöras och inte användas i projektet.

Det färdiga forskningsmaterialet kommer att bestå av ett antal bandinspelade och utskrivna intervjuer (som förvaras på en dator som inte är ansluten till någon server), samt anteckningar från våra möten (vilka förvaras inlåsta på mitt arbetsrum). Detta material kommer *endast* jag själv att ha tillgång till under projekttiden. Detta anomyniserade och avidentifierade material ska jag använda i vetenskapliga artiklar och publikationer. När projektet är avslutat överlämnas allt material till Folklivsarkivet vid Lunds universitet, där det kommer att vara skyddat enligt gängse bestämmelser. Information om forskningsresultat kommer att spridas på lämpligt sätt.

Att intervjuas i ett så känsligt ämne och privat ämne som Huntingtons sjukdom kan upplevas som både svårt och obehagligt. Du har rätt att när som helst avbryta en intervju eller ett möte om du skulle känna att samtalet kring sjukdomen och din situation blir för svårt eller obehagligt. Du har också rätt att avbryta all medverkan i projektet utan någon särskild förklaring. Alla kontakter mellan oss kommer att ske på ett respektfullt och korrekt sätt, där jag som forskare kommer att respektera dina önskemål i samband med alla våra möten. Du kommer kontinuerligt under hela projekttiden att kunna kontakta mig för att få svar på eventuella frågor samt framföra dina synpunkter kring alla våra kontakter.

Om du är intresserad av att delta i projektet så ber jag dig att kontakta mig på nedanstående adress. Jag kommer då att arrangera så att du får en samtyckesblankett på vilken du återigen kommer att finna de villkor som gäller för deltagande i projektet. Det också på denna samtyckesblankett som du accepterar att delta i projektet genom att kryssa i Ja-rutan, samt genom att skriva din namnteckning längst ner på blanketten. I samband med detta kommer du att få ytterligare tid att fundera över om du vill delta i projektet, och skulle du i samband med detta ändra ditt beslut kan du bara låta bli att skicka tillbaka samtyckesblanketten till mig. Du kan också förtydliga ditt nej till att delta i projektet genom att kryssa i Nej-rutan, samt skriva under längst ner på blanketten.

Min forskning är godkänd av den regionala etikprövningsnämnden i Lund

Niclas Hagen, doktorand

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Niclas. Hagen@Kultur.lu.se

LUNDS UNIVERSITET
Humaniora och teologi

BAGADILICO
Excellence in Parkinson and Huntington research

Etnologiskt forskningsprojekt om att leva med Huntingtons sjukdom

Institutionen för Kulturvetenskaper vid Lunds universitet kommer under 2010 att påbörja arbetet med att intervjua och följa människor som på olika sätt är drabbade av Huntingtons sjukdom.

Mitt namn är Niclas Hagen och jag är verksam som doktorand inom ett tvärvetenskapligt forskningsprojekt där etnologer samarbetar med medicinska forskare som har specialkompetens om Huntingtons sjukdom. Huvudansvarig för min forskning är professor Susanne Lundin vid Institutionen för Kulturvetenskaper och min biträdande handledare är docent Åsa Petersén vid Enheten för translationell neuroendokrin forskning, Lunds universitet.

I den etnologiska delen av projektet intresserar vi oss för hur människor som på olika sätt drabbats av Huntingtons sjukdom upplever sin livssituation. Vår forskning syftar till att studera hur framväxten av kunskap kring vår hjärna och dess sjukdomar införlivas i människors vardagsliv och hur denna ”vardagskunskap” samspelar med den medicinska och biologiska kunskap som tas fram inom den medicinska forskningen. Vi söker nu personer som på olika sätt är drabbade av Huntingtons sjukdom och hoppas att du är intresserad. Jag vill i ett intervjusamtal ställa frågor till dig om hur det är att leva med Huntingtons sjukdom. Utöver intervjuerna hoppas jag även kunna få träffa och följa dig i delar av din vardag: Att få träffa dig i din hemmiljö, i patientföreningen samt i samband med dina eventuella kontakter med hälso – och sjukvården.

All medverkan i projektet är helt fristående från all form av behandlingsverksamhet som sker inom hälso – och sjukvården samt kommunal omsorgsverksamhet. Detta betyder att ditt beslut om medverkan i projektet inte på något sätt kommer att påverka dina rättigheter eller möjligheter till behandling som ges inom hälso – och sjukvården eller inom den kommunala omsorgsverksamheten. Eventuellt deltagande i projektet är helt frivilligt och du har som deltagare rätt att när som helst avbryta din medverkan i projektet utan särskild förklaring. Varje deltagare i projektet bestämmer helt och hållet själv formerna för alla våra kontakter. Deltagarna har också rätt att när som helst avbryta en intervju eller ett möte om man skulle känna att samtalet blir för svårt eller obehagligt. Alla kontakter och intervjuer med projektets deltagare sker under tystnadsplikt. *Detta innebär att inget forskningsmaterial som inte är anomyniserat och avidentifierat kommer att spridas.*

För ytterligare upplysningar kring projektet är du är välkommen att kontakta Niclas Hagen på följande adress, telefonnummer eller e-post:

Niclas Hagen, doktorand
Telefon: 0707-43 50 16

E-post: Niclas.Hagen@Kultur.lu.se
Se även: http://www.kultur.lu.se/institutionen/personal/hagen-niclas,
http://www.med.lu.se/neurofortis/bagadilico

Institutionen för Kulturvetenskaper, avdelningen för etnologi, Lunds universitet
Biskopsgatan 7, 223 62 Lund

Appendix II

Interview guide

Intervjuguide

Om dig själv

- **Berätta lite om dig/er själv/själva? (Ålder, civilstånd, barn, yrke)?**

- ***Hur såg ditt/ert liv ut innan HS drabbade dig/er?***

”Sjukdomen”

- **Sjukdom: Kan ni berätta på vilket sätt ni är drabbade av Huntingtons sjukdom?**

(Stickfrågor i de fall då intervjupersonen vill ha ett förtydligande av frågan): – *HD-positiv av mutationen men symptomfri, - symptom (vilka?), - Ej testad, men HS i familjen, - Anhörig (i viket sjukdomsstadium befinner sig den drabbade?), - Testad och ej HD-positiv*

- **Berätta om hur ni veta att sjukdomen fanns i familjen?**

  Vem hade sjukdomen från början?

  Hur fick ni veta?

  Hur reagerade ni när ni fick veta

  Hur tänker ni kring allt detta idag?

Upplevelser och erfarenheter av sjukdomen

- **Berätta vad har sjukdomen gjort med Er/dig och er familj?**

  Hur har er släkt reagerat på sjukdomen?

- **Vilka symptom upplever ni som svårast?**

- **Hur ”tacklar” ni/du dessa i din vardag?**

- **Hur upplever ni att omgivningen och samhället ser på sjukdomen?**

  Kan du/ni berätta om någon speciell händelse i samband med detta?

- **Kan du berätta om dina/era upplevelser av de läkemedel som du tar för att mildra de olika symptomen?**

  Hur påverkas du/er anhörig av dessa läkemedel?

- **Hur ser du/ni på framtiden?**

Patient/anhörigförening (Om man är aktiv eller deltager i en sådan)

- **Berätta om ditt arbete i patient/anhörigföreningen? (om man är aktiv)**

- **Vad betyder patientföreningen/anhörigföreningen för dig/er?**

Huntingtons sjukdom och vård

- **Berätta om era erfarenheter med sjukvården och omsorgsverksamheten?**

- **Berätta om hur du/ni funderar kring detta med att testa sig för Huntington sjukdom**

  Alternativt: Berätta om dina funderingar inför ditt beslut att testa sig för HS?

Appendix III

Form for informed consent

LUNDS UNIVERSITET

Institutionen för kulturvetenskaper
Niclas Hagen, doktorand etnologi

Hej!

Stort tack för ditt intresse till att medverka i projektet! Ser fram emot att få ta del av dina tankar och erfarenheter. Varje person som är intresserad att medverka i projektet skall få sig tillsänd dels en förfrågan (som innehåller information om projektet) om medverkan, dels en samtyckesblankett som skall skrivas under av oss båda. Enligt det etiska ramverk som styr projektet så skall varje eventuell deltagare få möjlighet till en betänketid mellan en förfrågan om att medverka och översändandet av samtyckesblanketten. Därför sänder jag idag en förfrågan till dig, och skickar dig samtyckesblanketten (också via mail) på fredag. När du har fattat ditt beslut så kan du kontakta mig via telefon eller mail, för att diskutera när vi kan träffas för att genomföra intervjun etc. Du är alltid välkommen att höra av dig till mig med frågor etc. Du hittar mina kontaktuppgifter nedan samt i det bifogade materialet.

Tack och bästa hälsningar!

Niclas Hagen

Postadress Biskopsgatan 7, 223 62 Lund *Besöksadress* Biskopsgatan 7 Lund *Telefon mobil 0707-43 50 16, arbete* 046-222 41 88 *Telefax* 046-222 31 43 *E-post* Niclas.Hagen@Kultur.lu.se *Internet* http://www.kult.lu.se

Samtycke för deltagande forskningsperson i projektet:

Biomedicinska samspel: integrering och överföring av biomedicinsk kunskap från klinik till drabbad

Jag har tagit del av information som lämnats till mig om projektet *Biomedicinska samspel: integrering och överföring av biomedicinsk kunskap från klinik till drabbad*, och jag accepterar att delta som forskningsperson enligt de villkor som anges i den skriftliga informationen vilken överlämnats till mig i samband med en skriftlig förfrågan om ett eventuellt deltagande som forskningsperson i projektet. Denna skriftliga information anger följande villkor för deltagande forskningspersoner:

- Det är frivilligt att delta i projektet.
- Du kan när som helst avbryta din medverkan, utan att lämna en särskild förklaring till forskaren
- Du kan när som helst begära att allt forskningsmaterial kring dig inte används och att detta material förstörs
- Om du medger detta, kommer intervjumaterialet att arkiveras i Folklivsarkivet vid Institutionen för Kulturvetenskaper, avd. för etnologi, Lunds universitet. Informationen hanteras utifrån 7 kap. 24 § i sekretesslagen (1980:100). Detta innebär att när materialet lämnats till Folklivsarkivet respekteras forskningspersonens önskemål om sekretess i 50 år.
- Uppgifter om dig eller andra enskilda personer kommer inte att användas eller utlånas för kommersiellt bruk eller andra icke-vetenskapliga syften.
- Om du medger detta, kommer intervjuerna att spelas in. Du bestämmer om du vill att inspelningen skall avbrytas, om det inspelande materialet skall raderas efter projekttidens utgång eller vid ett tidigare tillfälle.
- Varje form av kontakt mellan dig och forskaren sker på en plats och vid en tid som bestäms av dig.

- Din medverkan som forskningsperson i projektet är helt fristående från all form av behandlingsverksamhet som sker inom hälso –och sjukvården samt kommunal omsorgsverksamhet. Detta betyder att ditt beslut om medverkan i projektet inte på något sätt kommer att påverka din rätt eller dina möjligheter till behandling som ges inom hälso –och sjukvården eller inom kommunal omsorgsverksamhet.
- Jag som forskare kommer under projekttiden att svara på dina frågor om projektet.

Denna överenskommelse undertecknas av forskningspersonen och forskaren

Jag accepterar att delta som forskningsperson i projektet biomedicinska samspel:

Ja ☐

Ort och datum **Namnförtydligande**

(Forskningsperson)

Ort och datum **Niclas Hagen**

(Doktorand vid Inst. för Kulturvetenskaper, Lunds universitet)

Paper I

Drinking glasses, doorsteps and table edges

-The material dimension of experiencing a genetic hazard

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Abstract

This article investigates and analyse a material dimension of experiencing a genetic hazard. The article performs this analysis on the basis of ethnographic material obtained within the context of Huntington's disease, a fatal genetic disease that affects the brain. The article analyses the role of household objects among individuals affected by the disease by identifying them as an example of what Sherry Turkle have termed as evocative objects, material objects that stand in a direct relationship with our emotional and intellectual being. These evocative objects stir anxieties and emotions among the affected individuals, but they also convey an experience of corporeal depth among those who face a genetic hazard. On the basis of Maurice Merleau-Ponty's phenomenological theory of an embodied existence, these evocative objects are seen as mediating ambivalent experiences among the affected individuals. As genetics and genomics continue to generate important and useful results for the society, one important challenge consists in addressing these embodied complexities and ambivalences.

Keywords: **Genetics, Huntington's disease, Experience, Materiality, Body**

Introduction

> ’Every time I dropped a cup, or my fingers moved on the steering wheel, or I tripped on a step I'd be thinking “oh my God, they are the early signs of Huntington's disease”. I didn't know what it felt like to think, “I'm having a bad day” or, “That step got in the way!”, it was a classic case of symptom hunting and it was quite a regular worry for me’ (http://en.hdyo.org/tee/articles/61).

These are the words of Naomi, taken from HDYO (http://en.hdyo.org) that is a website directed towards young people who in different ways are affected by Huntington´s disease, a fatal genetic disease that primarily affects the brain[1]. Naomi´s remark illustrates how a potential genetic hazard inside her body generates anxiety and uncertainty within her daily life. Previous research upon cultural and social aspects of genetics has often investigated and understood everyday life with a genetic hazard in terms of risk and as part of lay understandings of genetics (e.g. Cox and Mckellin, 1999; Forrest Keenan et al, 2007; Etchegary, 2009, 2010). However, in the citation above, Naomi points upon how various sorts of ordinary household objects came to play an important role in how she came to experience an uncertain, abstract and invisible genetic hazard situated deep within her own body.

I find Naomi’s remark interesting as it indicates that her experience of a genetic hazard does not revolve exclusively around lay understandings of statistical risk estimates and patterns of genetic inheritance. Instead, her experience of the uncertainty that she faces involves household objects that she encountered in her everyday life. This role of material objects is consistent to previous ethnological research of health related topics, where ethnologist Åsa Alftberg (2012) in her research upon the everyday experience of aging finds that among the participants in her ethnographic study, the daily experience of age and aging is something that revolves around various things that surrounds the participants in their

everyday life (Alftberg, 2012: 43-62). I do not deny the importance of those perspectives that defines and investigates experiences of a genetic hazard in terms of risk (e.g Kavanaugh and Broom, 1998; Rose, 2007: 106-131; Lock and Nguyen, 2010: 303-325). However, the point of departure for this article is slightly different, as it approach questions of risk and lay understanding of genetics from a level of human perception that precedes understandings of risk estimates and patterns of genetic inheritance. As noted by Evelyn Fox Keller and others, biological inheritance has, after the birth of genetics as a scientific discipline, come to be seen in terms of a separation between internal spaces of our body and our external environment (Fox Keller, 2010: 22; Nelkin and Lindee, 2004; Åkesson, 1999; Lundin, 1997: 75-104). Naomi's remark can thus not only be viewed as an experience of being at genetic risk, but also in terms of how we understand and perceive those internal spaces of our body that, in the words of philosopher and physician Drew Leder, 'recede from direct experience' (Leder, 1990a: 1). It is in conjunction to this more basal level of embodiment that various household objects attain their role and importance in the daily life of the affected individuals.

The aim of this article is to analyse how material objects forms an intrinsic part of an embodied experience of a genetic hazard and uncertainty. My analysis will be based on ethnographic material that was obtained as part of a study conducted in Southern Sweden 2009-2010 with individuals who are affected by Huntington's disease. The disposition of the article will be as follows: The first section of the article will provide an account for the theoretical framework used for my analysis, followed by the second section in which I will discuss the method employed in obtaining my ethnographic material. I will initiate my analysis in the third section of the article, where I intend to discuss the role and importance of household objects in terms of evocative objects for individuals affected by Huntington's disease. The following, fourth section, constitutes a discussion on how these evocative objects enable the affected individuals to perceive the corporeal depths of their own bodies. Then, in

the fifth section, I intend to show how this experience of corporeal depth is an unstable, due to the intertwining between overlapping but yet incommensurable understandings of our bodies. In the sixth and last section of the article, I will relate the implications derived from my analysis to the broader use of genetics and genomics within our society.

Theoretical framework

My analysis will be based on a theoretical framework derived from phenomenology, mainly from the philosopher Maurice Merleau-Ponty's (1968, 2002) expositions on the role of the body in perception, as well as parts of his later expositions on the relation between the invisible and visible in conjunction to perception and human existence in general. The main analytical concept to be employed for my analysis is what Merleau-Ponty designated as the chiasm. This concept describes our body's equivocal feature of a simultaneously beingd and perceived as an objective and subjective body. In other words, this intertwining between the body perceived as an object and the body as perceiving subject can be seen as a form of existential state of being (Merleau-Ponty, 1968, 2002). In addition to this, there is also a clear material dimension within Merleau-Ponty's phenomenological framework, as he sees material objects as an intrinsic part of our embodied perception and our existence within the world. This intrinsic materiality of our embodied existence comes about as various sorts of material objects are incorporated within all those corporeal schemas that underlie our daily practices, as well as our intentional actions (Merleau-Ponty, 2002).

Yet, in order to achieve a more broad understanding of the role of this material dimension within the embodied experience of the affected individuals, I intend to combine the above suppositions with sociologist and psychologist Sherry Turkle's (2007) concept of evocative objects. Turkle defines evocative objects as objects that stand in a direct

relationship with our emotional and intellectual being[2]. Turkle's concept emphasizes the intricate relationship that exists between material objects and humans, where various forms of material objects injects both an emotional and intellectual content within our daily existence. In this way, various sorts of material objects can be considered as 'companions to our emotional life or as provocations to thought' (Turkle, 2007: 5). In contrast to Merleau-Ponty's phenomenological analysis of the role of material objects in human perception, Turkle's concept direct us then towards the emotional and intellectual aspects that reside in material objects rather than, as with Merleau-Ponty, focusing exclusively on their role in human perception.

Method

The empirical material that forms the basis for this article is derived from semi-structured interviews performed with individuals who in various ways are affected with Huntington's disease. As stated previously, these interviews were performed as part of a study in Southern Sweden in 2009-2010, and in a similar fashion as with Naomi, the narratives of many of the participants who took part in the study contained remarks about household things in relation to their experiences of Huntington's disease. Sociologist Arthur Frank (1995) argues that the narratives that are told by individuals who are affected by disease come out of their bodies, and these stories are embodied as the body sets in motion the need for new stories when disease disrupts those that were told before the onset of disease. The body is simultaneously cause, topic, and instrument of these new narratives (Frank, 1995: 2). The presence of a material dimension within the narratives of the affected individuals might then also concern issues of our embodied existence and the perception of our own bodies. These narratives were obtained through semi-structured interviews were performed with eleven individuals in families that have been affected by the disease[3].

All interviews were performed solely by the author, and lasted between 1 hr 30 min. and 2 hrs and 30 minutes and were conducted in a place of the interviewees' choice. An interview-guide was employed for the interviews, but used in flexible way so the interviewees could go into various aspects regarding their daily life with Huntington's disease on their own terms. All interviews were recorded by the use of a digital voice recorder, and all interviews were subsequently transcribed in verbatim and analysed by the author. Moreover, in order to protect the privacy if the participating individuals, all names featured in the text have been changed in order to protect the anonymity of the participating individuals. The analysis of the transcribed material took place in several consecutive steps, where the first step constituted a reading of each manuscript was read several times until a number of themes were identified. In the next step, the different manuscripts were compared with each other with respect to these themes, and a table of overarching themes are organized as a way to summarise the result of the comparison made in the second stage of the analysis. In the last stage of the analysis these overarching themes were related to more general cultural and social theoretical frameworks. The study was performed as part of the Basal Ganglia Disorders Linnaeus Consortium (see (http://www.med.lu.se/bagadilico), which is supported by The Swedish Research Council [grant number 349-2007-8626]. The regional ethical committee at Lund University approved the study.

Evocative objects

Jimmy is in his thirties and lives, at the time of the interview, in one of the major cities in Southern Sweden. His mother has for some time been sick in Huntington's disease and even though he knew that the disease did run in the family, it was not until his mother's condition became visibly apparent, in the form of clear neurological signs and symptoms, that the potential personal danger became obvious for him. At this point in time, Jimmy was

convinced that he was carrying the mutated gene because his everyday life was all of a sudden filled with signs and symptoms:

> Jimmy: Yes, you took everything as a symptom […] Even if you had read that things were not a symptom it became a symptom. It is…no, it was an awful period.

In a similar fashion as with Naomi, these symptoms regularly showed up in relation to various objects, where seemingly random events such as a dropped glass or a stumble on a doorstep were seen as a sign of the presence of the mutated gene that causes the disease:

> Jimmy: You spill out things which I never do otherwise, you ran into edges and, I think my toes where blue and…well, it´s all the time.

Bradley is another participant in the study, who is in his twenties, and is at risk for being a gene-carrier for the mutated gene that causes the disease. When I ask him if he looks for symptoms of the disease in his everyday life, he answers that it happens. And when I ask him to describe how this might happen, his answer also illustrates how seemingly trivial things as a stumble on a doorstep becomes interpreted as a possible sign of the disease:

> Bradley: Ok, I stumbled…should I have stumbled there, kind of…yes.

Bradley´s mother Elizabeth also took part the interview and in conjunction to Bradley´s account above, she remembered the experiences of a relative of theirs who were at risk for Huntington's disease:

> Elizabeth: For maybe 10 years ago, she [Bradley´s and Elizabeth´s relative] was quite preoccupied with if she stumbled or fumbled. Oh! Does it [HD] start now? Is it coming now?

Daily life would be extremely difficult, as pointed out by anthropologist Richard Wilk (2009), if we did not have habits and routines. This becomes clear when our routines and habits are disrupted. Then, we suddenly 'have to become mindful of little things, think through details which we normally take for granted, and which have become deeply embedded and encoded in our built environment and possessions' (Wilk, 2009: 146).

However, routines are also deeply embedded with those things that we use in our everyday life. As stressed by Merleau-Ponty, there is a constant inter-relationship between our embodied self and material things in our surroundings. Indeed, often these things are seen as being incorporated, as part of a corporeal schema, within the intentional actions taken on through our bodies. These things becomes embedded within these routines and experienced as part of ones own body (Hass, 2008: 79; Merleau-Ponty, 2002: 164-165). The blind man's stick, as famously illustrated by Merleau-Ponty, has ceased to be a thing or an object, and is no longer perceived for itself, but rather as a part of blind man's own body and his intentional actions: 'To get used to a hat, a car or a stick is to be transplanted into them, or conversely, to incorporate them into the bulk of our body' (Merleau-Ponty, 2002: 165, 166). I mean this kind of embodied materiality is present in conjunction to such routines as drinking a cup of coffee, moving from one room to another, or driving one's car from one place to another. Ordinarily, and very much in the same way as Merleau-Ponty describes the interlacing between the blind man's body and his stick, all those household objects featured in the above citations were experienced as part of the participants' bodies when they performed various daily routines. However, when these routines are disrupted, these objects become disentangled from the kind of embodied interlacing that they hitherto had been part of. As a consequence of these disentanglements, these household objects take on a new meaning for the affected individuals. They become what Sherry Turkle has described as evocative objects.

In a similar fashion as with Merleau-Ponty, Sherry Turkle (2007) emphasizes the closeness between humans and material objects. According to Turkle, material objects can, as 'companions to our emotional lives or as provocations to thought', exert a substantial power over our life based upon the time and circumstance in which these objects come into our life (Turkle, 2007: 5, 8). She discusses this intimate relationship between material objects and us in terms of evocative objects. These evocative objects are objects that stir our emotions and provoke us intellectually, objects that 'brings together intellect and emotion' (Turkle, 2007: 5). These evocative objects are, as pointed out by ethnologist Jonas Frykman (2012), objects that we tend to think with rather than on them (Frykman, 2012: 103).

As a consequence of the disentanglement of the kind of embodied materiality, various sorts of household objects becomes become highly charged evocative objects for the affected individuals. To pass a doorstep when, for example, entering a room or a building is normally an occurrence that merely passes as a detail in our everyday life, most often our thoughts and attention are directed elsewhere and if we for some reason should stumble, the effect is probably a slight irritation or embarrassment. But for those individuals whom we meet above these kind of disruptions becomes something that provokes their thoughts and brings forward emotions about their genetic status and the prospect of being a gene-carrier. Was this just a "normal" stumble that occasionally happens to everybody, or was it something else and much more serious? As previous research as shown, this awareness is not constant in the daily life of the individuals. Instead, emotions and thoughts about the disease come and go with a varying intensity (Etchegary, 2010: 646; Kenen et al, 2003: 315-316; Parsons and Atkinson, 1992: 454), but as pointed out by Naomi in the introduction, during the most intense periods, the thought of just "having a bad day" in relation to a mishap easily disappears in favour of distressing thoughts and anxieties about your genetic status. In relation to this variation of the intensity by which the anxiety and uncertainty comes and goes in the

daily life of those affected, the ethnographic material presented above points upon the role of these evocative objects. As such, these evocative objects provoke both emotions and thoughts that obviously revolve around the prospect of a mutated gene and Huntington's disease. In other words, these evocative objects constitute an important source through which the affected individuals experience the uncertainty that arise in relation to their own genetic status.

In this section, I discussed how material objects take on a role as evocative objects in the daily life of the affected individuals, which raise both anxiety and awareness among the affected individuals of the impeding danger that are posed to them and their loved ones by the disease. However, there is still yet another side of these evocative objects that needs to be investigated in order to reach an understanding of the role attained by these objects within the daily life of the affected individuals. This additional side of these evocative objects revolves around the double belongingness of our body that Merleau-Ponty (1968) in his later writings came to describe in terms of a chiasm (Merleau-Ponty, 1968: 130-155).

The body as a thing with a corporeal depth

In order to investigate this additional role of these evocative objects, I need to make a further clarification of my statement that our body displays a double belongingness. According to Merleau-Ponty, there is a dual perspective of the way we perceive our bodies: On one hand, our body is experienced as a 'thing among things' but, on the other hand, the very same body is also experienced as a perceiving subject that constitutes the originating point for our perceptions and intentional activities in the world. In his later writings, Merleau-Ponty (1968) came to express these two simultaneous existential features of our body in terms of a chiasm because 'it is evident, that it unites these two properties within itself' (Merleau-Ponty, 1968: 137). He often illustrated this chiasm by invoke the way our hands take up a dual position of

being perceived (as an object among other objects) or as part of a perceiving subject and his/hers intentions: 'This can happen only if my hand, while it is felt from within, is also accessible from without, itself tangible, for my other hand, for example, if it takes its place among other things', and he continues to state that these two features 'are applied upon one another, as the two halves of an orange' (Merleau-Ponty, 1968: 130-155, 133). In relation this chiasmatic condition, philosopher Lawrence Hass (2008) notes that it seems like we are aligned to forget the body as we live out our daily lives (Haas, 2008: 77). Likewise Leder (1990a) points upon this actual absence of our bodies within our daily life. When reading a capturing book, for example,' one's own bodily state may, in most cases, be the farthest thing from my awareness' (Leder, 1990a: 1). Unless our bodies are haunted by illness, most of the times our daily life can therefore be characterized in terms of this absence. This is of course even more valid in conjunction to those parts of our bodies that resides within our corporeal depths, parts and entities that hardly ever at all becomes the focus for our awareness.

Subsequently, when the affected individuals performed their daily routines undisrupted by various mishaps, they did so on the basis of that side of the chiasm wherein our body is perceived as an intentional and perceiving body. Yet, in relation to the additional role of these evocative objects, I would like to suggest that we could discern a shift in how the affected individuals come to think and perceive their bodies. My suggestion is that these evocative objects mediate an experience of the body as a thing in-itself among the affected individuals. But in order to make my suggestion a bit more transparent, I would like to return to the ethnographic material and invoke a remark made from another of the participants in the study, Patricia, who knows that she sometime in the future will fall ill with Huntington's disease.

Patricia is in her mid-thirties and decided after her father fell ill to find out if her genome contained the mutated gene. She took a predictive genetic test that disclosed that she

did in fact carry the mutated gene. Yet, even if the test did disclose that her genome did contain the gene, the test could not say anything about when the disease will make debut. Currently, the formal diagnose of Huntington´s disease is put at the time when the individual present clear neurological signs and symptoms of the disease. At the moment, Patricia is, as a so-called pre-symptomatic patient, situated in a "border-zone" between health and sickness (Hagen, 2011). Compared to those individuals who are at risk, and for whom the crucial question is whether or not they are a gene-carriers, the question that now hunts Patricia is when the disease will make its debut in the form of clear neurological signs and symptoms. Nonetheless, as indicated in the citation below, different objects used by Patricia in her daily life still seem to take on a role as evocative objects. At the time of our interview, Patricia had in her spare time started to work in a catering firm; a job that occasionally meant that she had to serve guests at various events. These occasions could be stressful for Patricia, as a mishap could result in the same kind of reactions as for those who were at risk for the disease:

> Patricia: If I drop a glass, and it´s not like…the others drop glasses, as well. They also drop glasses when we have to serve champagne in a small and overcrowded room. And I don´t care about them dropping glasses, and it has not really happened a lot of times but for me it´s enough…for it´s enough with one glass. Everything that can happen to a ordinary person, but for us…for me it´s a kind of…

Naturally, this situation contains the same kind anxiety that we encountered with the other participants who were at risk for Huntington's disease, and for Patricia it is enough with one glass to provoke thoughts about a future that she knows will contain falling ill with the disease. On the basis of Patricia's remark, I then suggest that these evocative objects also invoked a change by which the affected individuals came to view their bodies as a thing among other things. That is, these evocative objects implored a change in bodily experience

that emphasized that side of the chiasm in which we come to look upon our body as thing among other things. Moreover, and drawing upon Leder (1990b), I also suggest that the emotional charge of these evocative objects arise just because these objects mediate the biological and existential power that is contained within the corporeal depth of these individuals, an elusive but nevertheless present power that 'that traverses me, granting me life in ways I have never fully willed nor understood (Leder, 1990b: 212). As Thomas, whose wife is diagnosed with Huntington's disease, says:

> Thomas: Yes, I think a lot about that darned gene, which is muta…which is wrong [not normal]

Elusive and abstract, yet powerful, the gene that causes Huntington's disease constitutes a genetic abnormality with grave and fatal consequences for those who are unfortunate to carry this mutation within their genome. For Thomas and his wife, Paula, the mutation is both tangible and very much apparent through its consequences. Paula has now reached that stage of the disease where she has clear neurological signs and symptoms, something that is not the case for those who are either at risk or are in the so called pre-symptomatic stage of the disease. Here, this direct linkage between corporeal depth and surface is still a feared possibility or, as in Patricia's case, a linkage that will establish itself sometime in her future. For them, the experience of corporeal depth and the power that is contained within their genomes is mediated through these household objects. It only takes a drooped glass for Patricia in order to make the invisible and mutated that causes the disease to materialize within her daily activities. This glass mediates the emotional and intellectual insight that deep inside her resides a gene that will force her body into a progressive malfunction that eventually will lead the loss of her ability to move and ultimately her existence in the world. This is also the case for those who were at risk for Huntington's

disease. However, for them this corporeal depth is still permeated with uncertainty, as it is still very much an open question whether their genome actually contains the mutated gene.

In this section, I have continued my analysis of the role attained by material objects in relation to a genetic hazard. In this section, I have, on the basis of Merleau-Ponty's analytical framework, discussed an additional role of those objects that I in the previous section defined as evocative objects. These evocative objects were found to mediate an experience on behalf of the affected individuals wherein they came to see their bodies as an entity that contains a corporeal depth. Moreover, these evocative objects also mediate an emotional and intellectual insight among the affected individuals of the power that is contained within their genome. Still, due to the chiasmatic features of our body, these experiences of a powerful corporeal depth is intertwined with the other side of the chiasm. In the next section, I intend to take a closer look on how this other side of the chiasm comes forward in the ethnographic material.

The other side of the chiasm

It is important to remember that the two features of the chiasm is not to be seen as fused with each other. They should rather be understood as interlocked but nevertheless separated and distinct features of our embodied existence; 'the two parts are total parts and yet are not superposable' (Merleau-Ponty, 1968: 134). Because of this circumstance, those situations in which the affected individuals perceive their bodies in terms of a thing with a corporeal depth can be viewed as moments that arise in conjunction to these evocative objects. These moments can, according to Merleay-Ponty, be 'no more than moments, and for most of the time personal existence represses the organism without being able either to go beyond it or renounce itself' (Merleau-Ponty, 2002: 97). This means that the other side of the chiasm, that side in which we experience our bodies as part of a perceiving subject, accompanies the kind

of bodily experiences that arise in relation to these evocative objects. In order to elucidate on this aspect, I would like to return to Jimmy's narrative and his reactions on the result of a predictive genetic test for Huntington's disease.

Jimmy took a predictive genetic test that showed that he did not carry the mutated HD gene, a result that of course change did his perspective upon many things in his life, including of course the prospect of starting a family. Yet, despite this outcome, there is a lingering uncertainty about the clearance offered by the result of the predictive test. When I ask Jimmy if he still looks for symptoms despite being cleared from risk by a predictive genetic test, his answer illustrates how the two sides of the chiasm always accompanies each other:

> Author: Do you look for symptoms?
>
> Jimmy: I'm not really looking for symptoms. But, this, these thoughts about the 50% pops up.
>
> Author: They do?
>
> Jimmy: All the time. Or, all the time, they often come back. In situations within the daily life. Makes things complicated, you know it's not like that I'm sort of tossing coins with myself. I did that a lot before I took the test, I sat and tossed coins with myself and guessed [about his genetic-status in accordance with the outcome of the coin tossing]…but I have stopped looking for symptoms, or it starts to…I think that if I bump into something, I'll not relate that to the disease as much as I did before.

As a response to the test result, Jimmy's daily existence seems to be almost free from evocative objects. Nevertheless, there is lingering uncertainty still present in his remark

in relation to the visibility of his corporeal depth offered through science and medicine. The thought of the 50% inheritance ratio of the mutated gene often comes back to him in his daily life. Before the test result, tossing a coin and visualizing his fate in accordance with the outcome, can be interpreted as a way to manage the random pattern of transmission that guides the inheritance of the mutated gene. A coin toss becomes a strategy for Jimmy to visualize and materialize this abstract but fateful randomness that determines whether his corporeal depth contained the mutated gene or not. The need for Jimmy to apply such a strategy has indeed also been reduced as a consequence of the test result, but the clearance delivered by the way of the predictive test is still perceptually elusive for him. This elusive aspect is also present in the narrative offered by Carla, who has two children who both took the decision to take a predictive genetic test in order to make find out if their genomes did contain the mutation. Neither of the children did carry the mutation but despite the test lies a few years back in time, Carla still have her doubts if the children's genome really do not contain the mutated gene:

> Carla: And I still have my doubts […] yes! And so have our kids. Like: Have they been fooling us, and are they waiting to see how we will react when we´ll get it.

I see both Jimmy's and Carla's reactions as a consequence of the chiasm that guides the way we perceive our bodies. The experiences made by the affected individuals are very much subjected to these overlapping but yet not fused features of our body. Moreover, as I have previously stated in this text, this later feature of the chiasm comes forward mainly through our senses that to a large degree is directed outwards towards the external world and not inwards towards the core of our corporeal depth. It is therefore not all together surprising that the information given by genetic science through predictive genetic testing is

accompanied by an uncertainty with regards to the actual meaning of the test result. On one hand, the body can be seen as an object with corporeal depth that contains genes. This is the kind of perspective that is endorsed and mediated by science as its focus is directed upon the mechanistic aspects of our body, as well as the various mechanisms behind the diseases that affects our bodies. On the other hand, though, this is body that is also an intentional and lived body prone to become absent in the mist of our daily lives. And it is this these kind of simultaneous but nevertheless distinct experiences of the body that gives rise to the kind of ambivalences discussed in this section.

I mean that we can see the above dynamics in conjunction to lay understandings of genetics. For example, within the context of Huntington's disease, Seymour Kessler and Maurice Bloch (1989) has described the phenomena of patient preselection (Kessler and Bloch, 1989). This term describes processes where other individuals, mainly within the affected family, or by themselves, choose individuals who are at risk to be a gene carrier for the mutated gene that causes the disease. Previous research has listed a number of aspects within the everyday life of those at risk that seems to increase the possibility for such a preselection. For example can a physical resemblance between the person at risk and an affected parent or a relative become the basis for a pre-selection (Kessler and Bloch, 1989; Cox and Mckellin, 1999), and anthropologist Margaret Lock (2008) has reported this linkage between physical resemblance and preselection also in conjunction to genetic susceptibility for early onset of Alazheimer´s disease (Lock, 2008: 70-71). Moreover, being in a form of social proximity, for example being the primary care-taker of an affected parent, can also form the basis for a preselection as to whom among a number of siblings might be seen as a gene carrier (Forrest Keenan et al, 2007: 124). In very much the same way as were the case with Jimmy's efforts above, the strategy of preselction also aims towards a management a genetic uncertainty hidden deep within the corporeal depth. What all these different strategies

have in common is their tendency to make the abstract notions of genetics manageable through visible and tangible aspects that are found within the everyday life of the affected individuals. In other words, the invisible and abstract causality that guides the inheritance of our genes is in all these cases reconfigured to level of visibility and tangibility that occurs alongside of those experiences of corporeal depth that I discussed in the previous section.

In this section, my analysis has been focused upon additional experiences that arise on the basis of the other side of the chiasm. The focal point of these understandings rests on various external features, on various visible and tangible factors on the surface of the body or within the daily social life of the affected individual. There is then a sort of alternating facet of the way the affected individuals experiences the doubt and uncertainty that comes with a genetic hazard such as the mutated gene that causes Huntington's disease.

In the next section, I intend to draw some concluding thoughts upon the implications of my analysis in relation to the use of genetics and genomics in our society.

Concluding thoughts: General implications of the chiasm

In this text, I have analyzed how experiences of a genetic hazard contain a material dimension. I showed how the uncertainty of a genetic hazard turns various households objects, drinking glasses, doorsteps and table edges, into evocative objects that mediates a specific embodied experience. As such, these evocative objects enable the affected individuals to visualize the corporeal depth that is the level of our bodies upon which genetic science operates and provides information upon. My analysis did however also yield a difficulty to fit this kind of genetic knowledge about our corporeal depth into an embodied coherent whole. I traced this difficulty to our chiasmatic feature of our own bodies. What kind of general implications in relation to developments within the molecular life sciences can be discerned on the basis of my analysis?

In her historical analysis of the nature-nurture debate Evelyn Fox Keller (2010) traces the historical origin of biological inheritance in terms of an ontological and epistemological shift. This shift revolved around the understanding of biological inheritance, which, after this shift, came to be understood in terms of a division between the internal spaces of the organism and the external environment (Fox Keller, 2010: 22). In relation to these internal spaces of the organism, sociologist Helga Nowotny and molecular biologist Guiseppe Testa (2010), states that one important and defining feature of the latest scientific developments within many of the molecular life sciences is their ability to 'make things visible that could not previously been seen' (Nowotny and Testa, 2010: 1). Naturally, when it comes to molecular biology and molecular genetics performed within the medical context, this enhanced visibility has to a large degree been achieved in relation to the corporeal depth of the human body and those molecules that can be found within such internal spaces as our cells and its nucleus. Yet, as Nowotny and Testa (2010) points out, "old" cultural and social frameworks are still very much present to guide our understandings notwithstanding these important and radical scientific advances. In relation to this simultaneous existence of discontinuity and continuity, they mean that these scientific advances and the increased knowledge about our biology will not automatically fit into a existing cultural and social framework to form coherent whole (Nowotny and Testa, 2010: 7, 12).

The previous sections of this article shows how this simultaneous existence of discontinuity and continuity arise in conjunction to the human body, which is very substrate for most of the scientific developments within genetics and genomics. The individuals whom we meet in the previous section have all encountered the sort of visibility that is offered by genetic science in the form of risk estimates and the information offered through predictive genetic testing. Due to the fact that genetics very much revolve around those parts of our bodies, our corporeal depth, that are not part those experiences and perceptions that governs

our everyday life, the sort of information that is offered by genetics easily induce complexities and ambivalences both on an individual as well as societal level (Wiszmeg et al, 2012). As pointed out by sociologist Ulrich Beck, late modernity has seen a proliferation of hazards that are neither visible nor perceptible to those affected, hazards that depends and requires the '"sensory organs" of science –theories, experiments measuring instruments –in order to become visible or interpretable as hazards at all' (Beck, 1992: 27). In the case of genetics, the interpretation of genetic hazards has very much been understood within a framework of probability statements that offers a rational and scientific description on the eventual transmission of a genetic hazard. This framework, however useful in many contexts, mainly offers a theoretical and scientized (Beck, 1992: 28) view of an experience that also revolves around our perceptions of our bodies.

My analysis of an intrinsic material dimension within the experiences of a genetic hazard shows, not only the complexity of the experiences made by the affected individuals, but also how our body's equivocal feature of a simultaneously being perceived as an objective and subjective body structures these understandings. Consequently, the embodied experiences that have been analyzed in this text constitute understandings that partly diverts from the more mechanistic perspective on our bodies that is offered by science. The implication of this diversion is that genetic knowledge cannot solely be viewed and acted upon on the basis of a nevertheless crucial scientific perspective. In relation to Nowotny's and Testa's prediction of our inability to forge the knowledge produced by the molecular life sciences into a coherent whole, we might come to the conclusion that parts of this inability have its basis in the kind embodied complexity investigated in this article. It then becomes important to take the embodied nature of these experiences into consideration alongside those perspectives that are produced by the rapid development by the molecular life sciences. As genetics and genomics continues to generate important and useful results for the society, one important challenge

consists in making those embodied complexities and ambivalences investigated in this article manageable within the clinical setting, as well on a more general cultural level. In relation to this challenge, a cultural analysis such as that preformed in this article will enable us as a society, not only to achieve a deeper understanding of those issues that are at stake as science increases our ability to examine our genome, but also to address these issues from a perspective that acknowledge the simultaneous existence of discontinuity and continuity that ultimately will guide the cultural and societal reception of an increased genetic capability.

Notes

[1] Huntington´s disease is a genetic disease caused by a mutation in one gene that codes for the Huntingtin protein and the pattern of inheritance is autosomal dominant, which means that a child of an affected parent have a 50% risk of inheriting the mutated gene (Huntington's Disease Collaborative Research Group**,** 1993). Huntington´s disease is characterised by a combination of neurological, psychiatric and cognitive symptoms (Petersén and Gabery, 2012). Currently, no treatment or cure exist for those who are affected by the disease. In general, the debut of the neurological symptoms is between 35 to 45 years of age, and the progression of the disease always leads to death within 15-20 years after the onset of the neurological symptoms (Ross and Tabrizi, 2011). These neurological symptoms include disturbances of mainly involuntary movements. The psychiatric symptoms is often present before the onset of the neurological symptoms, and they include such symptoms as personality changes, irritability and aggressive behaviour, as well as depression (Johnson et al, 2007; Julien et al, 2007). HD also includes cognitive disturbances that, in the later stages of the disease, progress to dementia (Stout et al., 2010). The clinical diagnosis for the disease is based on the presence of clear neurological signs in the affected individual (Huntington's disease Study group, 1996).

[2] During the past twenty years, research on the intrinsic bond between objects, humans and human culture has, under the thematic of material culture, developed into an interdisciplinary nexus that centres on the idea that materiality is an integral dimension of culture, and that are dimensions of social existence that cannot be understood without it (Tiley et al, 2009: 1). Within the field of science and technology, one of the most influential expressions of this development are, arguably, the numerous of research that originates from research made by Bruno Latour and colleagues (e.g. Latour and Woolgar, 1979; Callon, 1986).

[3] The participants of this study were recruited through advertisements at various websites aimed for individuals who in different ways were affected by Huntington's disease, as well as through personal visits (made by the author who did not know any of the participants before the study took place) to national and local meetings for affected individuals. As Huntington's disease is both a sensitive and difficult topic for many of those who are affected, the decision was taken on behalf of the author to let both the sample size and the determination of participants included in the study to be based only upon those individuals who came forward as a result of these advertisement and meetings. All of those who came forward and expressed a wish for taking part in the study were sent additional information (including an informed consent) and were also were given time to further reflect on their participation, as well as the informed consent. By relying upon this approach, the risk for adverse reactions on behalf of the participants due to the sensitive topic were seen as being minimized and all participants were given time to reflect upon their participation.

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Paper II

THE CULTURAL PARADOX OF PREDICTIVE GENETIC TESTING FOR HUNTINGTON'S DISEASE

Niclas Hagen

The aim of this article is to perform a cultural analysis of the effects and implications of predictive genetic testing for individuals who have undergone predictive genetic testing for Huntington's disease (HD). Moreover, the analysis aims to relate these effects and the implications of these tests to current initiatives that advocate a large-scale incorporation of genetics and genomics into mainstream health care. The abstract and elusive character of our genes is found to generate a liminal space wherein the affected individuals are situated between normality and abnormality. This juxtaposition of cultural classifications is in turn found to constitute a cultural paradox that might create disagreement in the relations between medical expertise and lay people as genetics and genomics is put to use within mainstream health care.

Keywords: predictive genetic testing, paradox, liminal space, Huntington's disease

I meet up with Jimmy, who is in his early thirties, in his apartment for an interview about his experiences of Huntington's disease (HD)[1], a fatal genetic disease that primarily affects the brain. Jimmy lives in one of the larger cities in the southern part of Sweden. He has a long-term relationship with his girlfriend. His mother has been diagnosed with HD, and as a consequence of the genetic laws that direct the inheritance of HD, the disease and its effects mark the family history on his mother's side of the family. The disease has been traced all the way to his grandmother's mother. Jimmy's mother has now reached that stage of the disease in which the affected individual shows clear signs and symptoms. In order to exclude other possible diagnoses, Jimmy's mother went through a diagnostic genetic test for HD that confirmed that her signs and symptoms were in fact due to Huntington's disease. Genetic testing is used partly as a diagnostic tool to differentiate between diagnoses, and partly as a predictive tool that gives information on carrier status and individual risk for future disease. As a diagnostic tool, the genetic test is performed in relation to more or less clear and visible signs and symptoms. A clear set of these signs and symptoms is usually not present in relation to predictive genetic testing, since the first appearance of the disease might lie several years, or even decades, in the future. The predictive genetic test for HD provides knowledge on the genetic status of those who choose to go through with taking the test. It does not however offer any knowledge about when those who are found to be gene-carriers for the mutated HD gene

will develop the disease (Kristoffersson 2010: 67–75, 89–98). Apart from confirming that his mother's signs and symptoms were HD, the genetic test and the subsequent diagnosis also put Jimmy at a 50% risk for having inherited the mutant HD gene.[2] Hitherto, Jimmy's own risk for inheriting the gene had more or less been something that resided in the back of his mind. The confirmation of his mother's HD-diagnosis comprised a transition point (Tibben 2007) that made the potential consequences of the mutant HD-gene obvious for Jimmy:

> That's when you'll get it, it's like a punch straight in your face. When you really understand that it's bloody serious. And that I'm in a fix here too…

At this point, Jimmy could either chose to wait and see what the future might hold for him. However, he could also choose to undergo a predictive genetic test that would disclose if, or if not, his genome contained the mutant HD-gene. If that were the case, Jimmy would be a genetic carrier or pre-symptomatic patient whose genome contains the mutated gene, even if clear signs and symptoms of HD are not visible at the time when the genetic test is carried out. Due to the scientific development within genetics, the different forms of genetic testing that are available have increased during the last decade and now encompass a range of conditions (Lock & Nguyen 2010: 330–331). In parallel with this increased medico-technological possibility, the prospect for disease prevention has been acknowledged. For example, a discussion article in one of the major Swedish newspapers from 2010 featured three biomedical researchers and experts writing strongly in favour for a wider use of genetic testing within the Swedish health-care system:

> A DNA-test would not necessarily make people more worried than other tests within the health-care system. Instead, they can give people an increased knowledge and tools that will enable them to reduce the risk for developing disease. (Björkegren, Nilbert & Syvänen 2010. My translation.)

Similar arguments can be found in the official report from the British Human Genomic Strategy Group on the use of genomics within the British health-care service:

> Genomic technologies have the potential to transform the delivery of healthcare in the UK, providing vital insights to support more accurate diagnosis of disease and inform therapeutic decisions – so that more patients get the right treatment at the right time. They can enhance preventive care and enrich our understanding of disease risk, as well as enabling outbreaks of infectious diseases to be controlled faster. (Human Genomics Strategy Group 2012)

These three "snap-shots" convey different viewpoints and different experiences of the ability to make various predictions of future disease in the absence of clear signs and symptoms. From a cultural perspective, these "snap-shots" raise a number of questions. What happens to those individuals who find themselves to be at risk for a genetic disease, and who choose the option of a predictive genetic test in order to receive knowledge about their genetic status? What salient issues can be discerned in conjunction with predictive genetic testing? How can these issues be understood from a cultural perspective? And what implications do these issues have in relation to the use of genetics and genomics as a predictive and preventive tool within mainstream health care?

Consequently, the aim of this article is to perform a cultural analysis, based on ethnographic interviews (see below), investigating the effects and implications of predictive genetic testing on individuals who went through predictive genetic testing for HD. The analysis also aims to relate these effects and implications to current initiatives advocating a large-scale incorporation of genetics and genomics into mainstream health care.

The analysis is guided by concepts obtained from studies in anthropology, ethnology, sociology, as well as science and technology studies. Victor Turner's concept of a liminal space is used as the main an-

alytical perspective. This captures a situation of being in between, as he terms it betwixt-and-between, stable and recognized cultural classifications (1979, 1977). Other important analytical perspectives are Åkesson's notion of the gene as an invisible "alien" inside the body (1999), as well as Nikolas Rose's idea of a somatic individuality (2007). Moreover, in relation to the notion of the gene as an "alien inside", the concept of embodied risk or danger also guids the analysis (Lock & Nguyen 2010: 303–329; Kavanagh & Broom 1998). Monica Konrad's notion of a cultural paradox that arises in relation to predictive genetic testing is employed in conjunction with a juxtaposition of normality and abnormality that was observed in the ethnographic interviews (2005: 82). Brian Wynne's investigations of relationships between experts and lay people are used for the section on effects and implications in relation to the utilization of genetics and genomics within mainstream health care. According to Wynne's standpoint, expert notions too often omit emotional and cultural aspects in favour of a more rational and calculative approach on important issues (1996). The concluding remarks of the analysis are built upon this standpoint when they state a necessity for mutual frameworks between experts and lay people in order to make predictive genetic testing sustainable when put to use in mainstream health care.

Regarding the aim mentioned above, HD functions as an illustrative case, as it represents a large group of devastating chronic diseases for which there are currently no cures available. The choice of HD as an illustrative case is a well-established research strategy, since the disease, despite the relative low number of affected individuals, has come to function as a "model disease" within the medical sciences, as well as within the social and cultural sciences. Within the medical sciences, HD shares clinical features with more common brain disorders such as Alzheimer's disease and Parkinson's disease for which there is no clear explanation concerning the causes of these disorders. Within the cultural and social sciences, HD has served as a "model disease" in relation to social and ethical issues, particularly in relation to predictive genetic testing, as HD was among the first genetic diseases where this form of genetic testing became available within the clinical setting (Tibben 2007; Brouwer-DudokdeWit et al. 2002). The predictive genetic test for HD has been available in the clinical setting since early 1993, following the discovery of the mutated HD gene. In Sweden, an informed consent is required to perform pre-symptomatic or predictive genetic investigations on HD. This means that the provider of the predictive genetic test, which in Sweden is provided by the national health-care system at a genetic clinic, has to be reassured that the individual who is taking the test has been given adequate genetic counselling. The provider must also ensure that the person undergoing the test understands the implication of taking the test. The testing process includes both a consultation with a clinical geneticist, as well as several meetings with a genetic counsellor. The process is designed to provide the individual with enough time to think through his or her decision and it is possible for the individual to withdraw from the testing process at any time. The result is given by a clinical geneticist and followed up at a meeting with a genetic counsellor even if the individual is found not to be a gene-carrier. The individuals undergoing testing and their family members should be offered psychological support suited to their needs. Results are usually followed up for a set period and according to a fixed schedule (Kristoffersson 2010: 95; Socialstyrelsen 2012).

The structure of the article is as follows. The article proceeds with a section on the methods employed in order to obtain the empirical material for this article. The next section will analyse the situation that faced the affected individuals as they discovered that they were at risk of inheriting the HD gene. After this, the consequences of predictive genetic testing upon this situation will be analysed. Finally, the analysis of the ethnographic interviews will be related to the use of genetics and genomics as a predictive and preventive tool in mainstream health care.

Method

A central concern in ethnography is the interpretation of matters that are at stake for particular par-

ticipants in particular situations (Kleinman 1997: 98). In order to understand the way people experience these particular situations, the ethnographic approach often displays a commitment to the particular; this is achieved by using small representative samples instead of larger samples resulting in quantitative generalizations (Smith, Flowers & Larkin 2009: 29–32). This approach will direct the ethnographer to collective (both local and societal) and individual (both public and intimate) levels of analysis of experience-near interests (Kleinman 1997: 98). This strategy within ethnography and ethnology has been employed in a number of studies that investigate different kinds of issues within the context of health (e.g., Alftberg 2012; Browner & Preloran 2010; Lock & Nguyen 2010; Hanson 2007; Konrad 2005; Lundin 1997; Klein 1989).

The ethnographic material for this article was obtained in southern Sweden in 2009–2010 as part of the Basal Ganglia Disorders Linnaean Consortium (Bagadilico) (http://www.med.lu.se/bagadilico). Bagadilico is an interdisciplinary research consortium at Lund University focusing on Parkinson's and Huntington's diseases. The study was performed with individuals who in various ways are affected by HD.[3] The empirical material mainly consists of in-depth interviews with the participants, whereas observations (which were recorded in the author's field diary, directly after the completion of the interviews) were used as an additional source of knowledge employed in the subsequent interpretation of the interviews. Following Alftberg (2012), it has to be acknowledged that the in-depth interview at times might be seen as a combination of verbal reports and ethnographic observations. The totality of the situation, not only what is verbally reported by the informant, forms the basis for the knowledge produced through the in-depth interview. Here, Alftberg uses the concept "ethnographic interview" as a way to capture this combination of verbally reported material and ethnographic observations (Alftberg 2012: 22). In relation to this article, the ethnographic interview provided an in-depth explorative and detailed knowledge of the experiences reported by the affected individuals. Apart from the knowledge reported verbally, it also included other aspects that came forward in the interview situation (for example in relation to emotional expressions such as crying at certain points in the interview). The names of the participants have been anonymized in order to protect their privacy. The study was approved by the regional ethical committee at Lund University.

An Invisible "Alien" Inside

Those things and aspects of our existence that, for different reasons and within different contexts, are considered unfamiliar or "alien" have always carried a powerful cultural charge (Åkesson 1999: 121). Arranging different phenomena into cultural classificatory systems is a well-known strategy to create order and control in a world that otherwise would stand out as chaotic and incomprehensive (Åkesson 1991: 57; Lundin & Åkesson 2000: 11). Within the cultural and social sciences, the importance and function played by different classificatory systems is a thoroughly investigated topic (e.g., Foucault 2002; Bowker & Star 2000; Frykman 1993; Åkesson 1991; Douglas 1966).

Within medicine, albeit with a great cultural diversification, classificatory systems are employed in order to diagnose illness and normalize health (Kleinman 1997: 22). These medical classifications split up the world of signs and symptoms into useful categories and models; this became crucial in conjunction with the growth of the modern state (Bowker & Star 2000: 101, 111). For example, the origin of the International Classification of Diseases (ICD) can be traced to the development of the welfare state and its concern with large-scale public health measures and programmes (Bowker & Star 2000: 111, 139–140). And, as noted by Michel Foucault and numerous others, these classifications can also be seen as entwined with the exercise of power within modernity (Hacking 2002: 99–114; Foucault 2000; Lupton 1995; Nelkin & Tancredi 1994).

Traditionally, these "alien features" of our existence were located externally, through such obvious visible criteria as skin colour or sex, which made them easy to incorporate within cultural categorizations. In conjunction with the context of disease,

this aspect can be exemplified by breast cancer. During the eighteenth and nineteenth centuries predisposing causes of breast cancer were traditionally understood in terms of outside influences, like injuries, childbearing, ethnicity or belonging to a certain age group (Schlich 2004: 212). Yet, during the twentieth century, heredity factors became increasingly important as a predisposing factor in relation to disease, often with reference to the developing field of genetics (e.g., Fox-Keller 2010; Nelkin & Lindee 2004; Petersen & Bunton 2002). Disease hazards and predispositions, these "alien features" of our existence, are relocated from various outside influences to the internal aspects of our body; this represents a process wherein these dangers and hazards become embodied (Lock & Nguyen 2010: 303–329; Kavanagh & Broom 1998). Epidemiologist Anne Kavanagh and sociologist Dorothy Broom consider that these embodied predispositions, these internal "aliens inside", are different compared with external hazards and predispositions because "they impose their threat from within – a person both has and is a body" (Kavanagh & Broom 1998: 442).

Today, genetics and genomics are to a large extent centred on the molecular constitution of the human body; DNA, RNA, proteins and various types of other molecules interact with each other and build up the body. New knowledge on our molecular constitution is seen as having profound implications, since it offers a greater understanding of the finest details of disease processes. Moreover, the impact of this development might also be seen within the context of diagnosis and prevention of disease, as it offers a more precise measurement of disease processes and even a reconceptualization of disease classifications (Shostak 2010: 251–254; Rose 2007: 13). According to Nikolas Rose, this development has the potential to reorganize the relations between individuals and biomedical expertise through a reshaping of the way in which human beings relate to themselves. Increasingly, we see and describe ourselves as "somatic individuals", as beings "whose individuality is, in part at least, grounded within our fleshy, corporeal existence, and who experience, articulate, judge, and act upon ourselves in part in the language of biomedicine" (2007: 6, 25–26). However, the anthropologist Monica Konrad points out that this picture might be too simplistic, as individuals are not "simply passive recipients of information given to them by clinical professionals" (2005: 63). The ethnographic interviews made within this study involving the experiences among the participants of being at risk, indicated that the participants evaded the idea of the statistical 50% ratio, which only gives a general depiction of the pattern of inheritance concerning this embodied danger that the participants faced. Instead of this general statistical notion, the participants tried to make sense of this potential and abstract "alien inside" by invoking various perceivable aspects within their everyday life.

Patricia is in her thirties and lives in a medium-sized town in the south of Sweden. She has no children and at the time I met her, she lived on her own. Patricia's situation resembles Jimmy's, as she came to understand the significance of HD and what it meant for her own future when Peter, her father, was diagnosed with the disease, who in turn inherited the mutated gene from his mother. At the point of her father's HD diagnosis, Patricia found herself at risk for having inherited the mutant HD gene and she came to the conclusion that she wanted to go through predictive genetic testing in order to find out if she carried the mutant HD gene. However, before she did the test, she tried to make sense of the circumstance of her being at risk by thinking in a way that was tangible for her:

> Yeah, you know… when you start adding up on things, you can't really put your finger on it, but if you ransack yourself, if you really look at the whole picture, you do feel, in some sort of way, that: Yes, that's the way it is. Of course, I have it. And then I told my mother and the rest of the family: Yes, I have it. Because I did get poisonous goitre from my grandmother, and I… if something strikes… something strange, then it strikes me.

At this point in time, Patricia did not have any knowledge of whether she in fact was a gene-carrier for the mutated HD gene, but despite this ambigu-

ity of her genetic status, Patricia pinpointed herself as a gene-carrier for the HD gene. She came to this conclusion on the basis of a perceived resemblance (the poisonous goitre) with her grandmother who had already developed HD. Jimmy's reaction on his mother's HD diagnosis provides an additional illustration:

> I was completely convinced that I was carrying the gene. So, I went around and checked, planned what I wanted to do during my last ten years alive. What I wanted to do before I was afflicted, that is. Whatever you do, you'll notice a symptom; you spill something, you drop something. Yes, it's symptoms all the time.

As a consequence of his mother's diagnosis, perceived signs and symptoms of the mutant HD gene mentally dominated Jimmy's everyday life. This aspect was also illustrated by a remark made by Carla, who is in her late fifties and is affected by HD through her husband. At the time of the study, he had recently passed away due to the disease. Carla has two children and they both decided to go through with the predictive testing to resolve their genetic status. They were both found to be non-carriers, but before they were tested, their everyday life was also very much dominated by the prospect of being a gene-carrier: As Carla puts it: "Before they were tested? Oh, yes! Every time something happened... oh, now I've got it."

When the participants learnt that HD ran in their family, their everyday life became filled with perceived signs and symptoms of HD; seemingly random accidents, like dropping something, were taken as palpable signs of the mutant HD gene. Likewise, perceived resemblances, like a shared history of coming down with the same diseases, were also taken as palpable signs of an abnormal genetic status (cf. Shostak, Zarhin & Ottman 2011; Konrad 2005: 61–86). At this point, no knowledge of the participant's genetic status existed, apart from the 50% ratio that constitutes a general and statistical description of the inheritance pattern of the HD gene. Nevertheless, from a cultural perspective, the experiences of the participants were that of being situated between the cultural classifications of normality (being out of danger) and being abnormal (being a gene-carrier). It should also be highlighted that these experiences of being situated between normality and abnormality also included an element of time. As shown in the citations above, the participants fluctuated in time between their present status of being at risk but not yet tested, and an eventual future status of actually being afflicted with HD. The participants seemed to move directly from the present into an anticipated future on the basis of perceived signs and symptoms of an abnormal genetic status, which they come across in their everyday life.

These unclear and indistinctive conditions can be understood, as mentioned above, through Victor Turner's term "liminal space". The term conceptualizes an existence betwixt-and-between different stable and recurrent conditions that are culturally recognized (1979: 467, 1977: 36–37). Inspired by folkloristic research on rites of transition and ritual processes, Turner discerns three phases in these rites. The first phase constitutes a separation, when the subjects who go through the ritual process are detached from their old places within the society. The intermediate phase occurs when the subject is betwixt-and-between recognized cultural classifications. In the third phase of re-aggregation, the subject returns to a new place or position within the community or society (1977: 36–37). Turner characterizes the intermediate phase as a liminal space within which ordinary cultural and cognitive classifications do not apply. Subjects who are situated within this liminal space cannot be understood and categorized through clear-cut cultural classification as they, being "betwixt-and-between" are "neither-this-nor-that, here-nor there, one-thing-not-the other" (1977: 37).

The ethnographic interviews indicated that the response of the participants could not be seen in terms of a passive reception of the 50% risk of inheritance of the mutant HD gene. Instead, an active and highly emotional response could be seen among the affected individuals that could be understood in terms of a juxtaposition of normality and abnor-

mality that involved a fluctuation between being at risk and being afflicted with HD. In other words, the everyday existence of these individuals can be understood as being betwixt-and-between normality or abnormality. Monica Konrad considers that this juxtaposition of normality and abnormality can be seen in terms of a cultural paradox (2005: 82). Thus, to enter this liminal space means that you are forced to manage this cultural paradox and the emotional responses that arise as a consequence of an existence betwixt-and-between these two recognized cultural classifications. The ethnographic interviews indicated that this management came to rely upon aspects that were perceivable within the everyday life of the affected individuals. As a way to rework the unclassified betwixt-and-between character of this liminal space into something that was manageable and possible to categorize as either normal or abnormal, they ascribed accidental events or resemblances with an HD-affected relative as a sign of the mutant HD gene.

What happened then when individuals went through with predictive genetic testing for HD? What impact did the knowledge of whether the affected individuals did or did not carry the mutated HD gene have upon their situation? Were they still situated within this liminal space?

The Impact of Predictive Genetic Testing

Both Jimmy and Patricia decided to go through with taking a predictive genetic test for HD. Here their paths start to diverge, because Jimmy's test revealed that he did not carry the mutated gene. Patricia however, was found to be a gene-carrier and will eventually develop HD. As a consequence of her test result, she obtained a status as a gene-carrier or a presymptomatic patient but, as will be shown below, this status did not alleviate Patricia's uncertainty as she struggled to cope with the result of the predictive test. This was also the case for her mother, Emma, who now had to face the difficult fact that the disease would definitely not stop with Peter, her husband, but would also affect her daughter as well.

For Emma, who is in her late fifties, Peter's diagnosis spelled out a future marked by a possible continuation of HD in her family, but Peter's diagnosis also involved a relief as the family got an answer explaining Peter's irritability and at times aggressive behaviour:

> Now I have the answer, you know. And now I know why certain things happened. Because he was… I did come in for a lot of physical stuff, you know. And it could be about such a thing that I'd cooked the wrong kind of dinner for him.

The psychiatric symptoms of HD include personality changes, irritability and aggressive behaviour, as well as disturbances in a person's state of mind, such as depression. The loss of cognitive functions includes deficits of memory and attention, which progresses to dementia in the later stages of the disease. For the affected individual and the family, the psychiatric and cognitive disturbances more than often constitute the most difficult and distressing features of HD, even though these signs and symptoms may appear as less striking compared with the more visible motoric signs (Ross & Tabrizi 2011; Petersén 2001: 16).

Carla's HD-stricken husband also displayed behaviour that at times was troublesome, which nevertheless struck Carla as being part of his personality up until genetics provided a confirmation of HD:

> Yes, when we came to know [about HD] I understood certain things that were present already when we met, like his urge to be in control (---) He wanted to know everything about what I did and things like that. But at that point, I thought that this was part of his personality.

Carolyn, who is of the same age as Carla and Emma, and has children who at the time of our interview had not undergone the predictive genetic test, also reports the same kind of thoughts. Carolyn's husband was diagnosed with HD at quite an old age, and in our interview she also talked of the diagnosis in terms of a disclosure that gave an explanation of past experiences: "With all the answers in my hand, I can see a lot of symptoms going on many, many years

back in time. Today I can connect this to Huntington but at that time I didn't, of course."

The crucial point in the cases above resided in the presence of clear and visible neurological signs, which a diagnostic genetic test confirmed as being HD. Therefore, within the context of diagnostic genetic testing for HD, the affected families were able to incorporate the result of the test into a cultural classification that permitted the affected individuals to review past events as a consequence of a disease and thereby being of an abnormal kind. This, however, did not necessarily seem to be the case for those who went through predictive genetic testing, when clear and visible signs were more or less absent. For Jimmy, predictive testing showed that he did not carry the abnormal HD gene within his genome. However, despite the test result, there still resided a small but lingering uncertainty in Jimmy's mind weather he was carrying the HD gene or not:

> No, but it is just that I don't know anything about all this; I was not present during the [analysing] process. I haven't seen all those machines that do the work. I don't really know how… how it works. The only thing I know is that they got my blood. That's all I know.

This was illustrated by the uncertainty reported by Carla's response to the test result of her two children, who were found not to be HD-gene carriers: "And just this; somebody telling you that you will not be afflicted, or that you will come down with it. Ok, but what does that really mean? That I will develop it. Or that I will not get it?"

Due to the abstract and invisible character of our genes, the result of the predictive test could not be attached to something obvious and concrete. This basic condition, which is an intrinsic aspect of predictive genetic testing, made it difficult for the affected individuals to create a stable and coherent understanding of their test result and of their genetic status.

Carla's thoughts are significant in those instances when the test result showed that the genome did contain the mutant HD gene.

The first meeting that I had with Patricia took place at the public library in her hometown, and there was nothing in her appearance that gave away that she was a gene-carrier for HD. For me she seemed to be perfectly healthy, with no trace of anything near HD. However, when we later met for conducting an in-depth interview Patricia told me about the symptoms that she in fact could perceive. These symptoms resembled those she had encountered during her childhood and her adolescence, when she and the rest of the family were faced with Peter's mood swings:

> Yes, it's this… exactly. These somewhat unbalanced [mood swings]; I can get really, really angry. But that's it, as I said previously and today I can say the same, I can get really angry but there's people who become furious and can get wild without having HD (…). But there's this extra dimension, it's hard to explain but it's this extra dimension, so to speak.

In this quote, Patricia identified her own mood swings as abnormal. She could perceive a difference, an extra dimension, which set apart the way she reacted and what she saw as a normal type of reaction. However, in relation to the presence or non-presence of symptoms there was also ambivalence in her experiences; this became apparent at a later stage in the interview when Patricia talked about the test result and about things that were actually happening to her. Things that might be clear signs of the disease:

> I feel both relieved and afraid. Yeah, I'm relieved because I feel just like anybody else, I feel energetic and… well, no problems at all. But at the same time I'm really scared because I feel and sometimes I can think: Oh, shit there's actually something that is happening with me.

Up to this point in the interview, I noticed how Patricia had been composed when she talked about HD and her difficult situation. I knew from our initial meeting at the public library that she was quite used to talking about the disease, but at this

point the emotions were coming through and she started to cry slowly. Something was happening to her. Despite the fact that she felt healthy, she also sensed that something was actually going on inside her body. Ambiguous bodily signs that she had not been able to grasp up to this point were now marking their presence in her everyday life. Patricia's experiences might also be associated with Jimmy's statement about not being able to really fathom the abstract process whereby his genome was found to be free from the HD gene. The only experience that Jimmy had about this process was his blood sample from which his DNA was extracted. For Patricia, the discovery that her genome did contain the HD gene was similarly a knowledge that had its origins in the same abstract and remote technological process. This remote technological process revealed that she sooner or later would develop a disease with a pathological appearance that was still quite intangible with her appearance of being a healthy individual.

The two quotes showed that Patricia, despite the knowledge she had about her genetic status, still experienced her situation as being betwixt-and-between normality and abnormality. A similar observation is made by Konrad who means that "the classificatory line between the categories of the pre-symptomatic and the symptomatic resists unambiguous differentiation as separate diagnostic entities" (2005: 81). This kind of collapse of classificatory lines is also observed in conjunction with other medical conditions, where Forss, Tishelman, Widmark and Sachs report that women who are notified of having cellular abnormalities when screened for cervical cancer are projected into a "liminal state" where "neither health nor disease was confirmed or excluded" (2004: 307). Undergoing predictive genetic testing offered no direct possibility for the affected individuals to clarify themselves as normal or abnormal with respect to HD. Instead of a clarification of their classificatory status, it seemed that both carriers and non-carriers stayed within the liminal space despite the knowledge offered by the predictive genetic test.

To be exposed to this liminal space with its cultural paradox may not only have caused an emotional effect on those who are situated within the liminal space. It may also pose a radical challenge to the Western biomedical notion of the patient as someone who demonstrates a clear and unambiguous cluster of detectable signs and symptoms (Konrad 2005: 82; Sachs 1995: 504). This later aspect came forward in the ethnographic interviews, and it did so mainly in relation to the diagnosis of HD. Currently, the formal HD diagnosis is made when clear motor symptoms appear, a circumstance that Patricia objected against:

> Ok, now they're calling me a gene-carrier. But who is saying that? And who has the right to say that, you know? Saying that from now on you're unwell. From now on, although up to that day when somebody says that you're afflicted you're only a gene-carrier. It kind of feels like that I'm not included.

Despite the situation of being betwixt-and-between normality and abnormality, Patricia still made a claim for the power over those classifications that ultimately define her as afflicted or not afflicted with HD. According to Patricia, this power was not to be held by the medical expertise alone, but should also be granted to the affected individuals. Patricia's reaction illustrates how this cultural paradox not only has an impact on the everyday life of the affected individuals, but how it also contains a struggle over definitions and interpretations between those who are situated within this liminal space and various experts.

In the previous sections, I have shown how the abstract and elusive character of our genes give rise to a liminal space within which the affected individuals are situated as a consequence of being at risk for developing HD. To be situated within this liminal space give rise to intuitions, emotions and actions among the affected individuals that include fluctuation between the present and an anticipated future in their everyday life. From a cultural perspective, these responses and actions on behalf of the affected individuals are seen as a result of a cultural paradox that arise from a juxtaposition of normality and

abnormality within this liminal space. Undergoing predictive genetic testing does not appear to resolve this situation. Despite the knowledge of their genetic status, revealed through the predictive genetic test, the affected individuals are still situated within this liminal space with its juxtaposition of normality and abnormality. As a consequence of this juxtaposition, the boundaries that separate the categories of being at risk for HD, being a pre-symptomatic gene carrier or being symptomatic and afflicted with HD are dissolved in the everyday life of the affected individuals.

As the possibilities of making various disease predictions on the basis of genetic and genomic knowledge expand, the issues that have been investigated above might apply to a far greater number of individuals than those who are affected by HD. In relation to this expansion, the proclaimed right on behalf of those who are situated within this liminal space to define the boundaries of normality and abnormality raises questions regarding the relationship between lay people, medical expertise and the health-care system.

Genetic Preventions in Mainstream Health Care

Currently, genetics is partly transformed from being a diagnostic tool, used in the presence of clear and visible symptoms, to a predictive and preventive tool. When this predictive tool is implemented in mainstream health care, the cultural paradox that was accounted for in previous sections can become relevant in relation to other diseases as well. Preventing a disease might of course imply finding a cure, but today prevention has also taken on another meaning, which according to Nikolas Rose aims at making the future "the subject of calculation and the object of remedial intervention" (2007: 19). A central point in this undertaking is to clarify the consequences of a harmful lifestyle, as well as to provide behavioural choices for people so that individuals can make informed decisions on matters of health and health-related behaviour. Here, the growing understanding of genetics and genomics is seen as a significant contribution (Human Genomics Strategy Group 2012: 34). The two citations given in the introduction showed how the prospect of genetic prediction is framed by medical expertise in terms of offering the individual citizen access to a powerful source of information in order to maintain or restore health. This desire for a future, open for calculation and medical intervention, can also be seen in economic terms, as the state tries to release itself from some of the responsibilities of the consequences of illness and accident that it acquired during the twentieth century (Rose 2007: 19, 63). In this cultural and political setting, every citizen is required to take an active role for securing his or her well-being (2007: 63).

An increased knowledge about the role of genetics and genomics in relation to disease offers great potential for alleviating suffering in various conditions. For a number of these diseases, such as cancer, preventive efforts and early detection is crucial in order for medicine to be applied to save lives. However, a realization of this potential depends, as noted by the Human Genomics Strategy Group, on "public trust in the application of technologies in diagnosis and treatment" (Human Genomics Strategy Group 2012: 79). An important measure in order to safeguard public engagement and trust in the use of genetics and genomics is education of the public on issues relating to genetics and genomics (Human Genomics Strategy Group 2012: 79). However, the relationship between scientific expertise and lay people also depends upon the acknowledgement of interpretative differences between the two groups. Sociologist and STS-scholar Brian Wynne makes the critical remark that expertise of all sorts often "tacitly and furtively impose prescriptive models of the human and the social upon lay people" and that these prescriptive models are "implicitly found wanting in human terms" (1996: 57). The critique of Wynne is directed towards conceptions of lay people in which their response towards expertise is seen in terms of a rational-calculative model. The main critique made by Wynne towards this model concerns the way it put too much emphasis on cognitive dimensions at the expense of the cultural dimensions of public response to expertise (Durant 2008: 7). In-

stead, all prescriptive models on the relationship between lay people and expertise have to acknowledge the "need to recognize hermeneutical differences" (Wynne 2008: 22) which might arise and even diversify the relationship between scientific expertise and lay people.

Predictive genetic testing for HD harbours, as shown by the ethnographic interviews, a cultural paradox in relation to classifications where the invisible "alien" inside give rise to intuitions, emotions and actions that are quite far removed from those rational and calculative approaches that are envisioned in the citations in the introduction. The ethnographic interviews reported in this article also showed that knowledge about whether the participants did or did not carry the mutated HD gene did not totally resolve these hermeneutical differences. Even though the knowledge provided by the predictive test resolved the issue of the participants' genetic status, there still seemed to exist a hermeneutical difference in relation to the question of normality and abnormality. This difference points towards the challenges that reside in conjunction with a large-scale implementation of genetic tests in the healthcare system, since notions of genetic risks and genetic status seldom contain neutral aspects. This absence of neutrality continued to mark its presence in the empirical material on HD, despite the fact that the predictive genetic test itself provided a clear-cut answer about the genetic status of the participants. Furthermore, these challenges concern not only those who are directly involved, patients and medical expertise, but also those social and cultural scientists who study the scientific development within genetics and genomics from various disciplinary viewpoints.

In relation to these differences between lay people and scientific expertise, the importance of an establishment of a mutual framework becomes a crucial measure in order to avoid a diversification and alienation on behalf of those affected. These mutual frameworks have to acknowledge the multiplicity of meanings, viewpoints and practices that exists in relation to predictive genetic testing, as well as the informational requirements generated by this multiplicity (Bowker & Star 2000: 297). The establishment of such a common framework between lay people and scientific experts would make predictive genetic testing and disease prevention sustainable if it is to become part of future mainstream health care.

Notes

1 Huntington's disease is caused by a mutation in the HD gene and the pattern of inheritance is autosomal dominant, which means that a child of an affected parent has a 50% risk of inheriting the mutated gene (Huntington's Disease Collaborative Research Group 1993). In Sweden, the prevalence of HD is about 1/17,000 individuals (Kristoffersson 2010: 94), which means that there is about 1,000 individuals who are diagnosed and afflicted with HD. The disease is characterized by a combination of neurological, psychiatric and cognitive symptoms. In general, the onset of the neurological symptoms appear at an age of between 35 to 45 years, and the progression of the disease always leads to death within 15–20 years after the onset of the neurological symptoms (Ross & Tabrizi 2011). The formal clinical diagnosis is based on the presence of unequivocal signs of motor dysfunction (Huntington Study Group 1996). These neurological symptoms include disturbances in the movements of the afflicted person, mainly causing involuntary movements. The psychiatric symptoms of HD, which most often are present before the onset of the neurological symptoms, include personality changes, irritability and aggressive behaviour, as well as depression (Johnson et al. 2007; Julien et al. 2007). HD also includes cognitive disturbances including deficits in attention that progress to dementia in the later stages of the disease (Stout 2010).

2 The concept of risk has been crucial in relation to genetic diseases; it has been investigated from a wide range of disciplinary approaches (e.g., Shostak, Zarhin & Ottman 2011; Lock & Nguyen 2010; Etchegary 2009; Hallowell et al. 2004; Cox & McKellin 1999; Kessler & Bloch 1989).

3 Eligible participants in the study were those who in various ways have come in close contact with HD. Participants were recruited through advertisements on the Internet, as well as through personal visits made by the author to various meetings for HD affected individuals held by patient organizations. HD is a sensitive and difficult topic for many of those who are affected. Consequently, the decision was taken to let the number of participants included in the study be based only upon those individuals who the author came in contact with as a result of these advertisements and personal visits. These individuals were then sent additional information (including the format for informed consent) and

were also given time to further reflect on their participation and on the informed consent. Semi-structured interviews were performed with eleven participants at a place of their choice, and the interviews lasted between 1.5 and 2.5 hours. An interview guide was employed for the interviews, but used in such flexible way that the interviewees could go into various aspects regarding their experiences of HD on their own terms. All interviews were recorded by the use of a digital voice recorder, and all interviews were subsequently transcribed *in verbatim*, and each transcript was then read and re-read until a number of themes were identified in the transcript. All citations from the interviews used in this article have not been altered into grammatically correct English, but kept in their original format.

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Paper III

CHAPTER 2

A molecular body in a digital society

From practical biosociality to online biosociality

Niclas Hagen

The background for this essay is two prominent and major developments within late modern society and culture. The first of these two developments concerns the human body and scientific developments in genetics and genomics, which continue to generate new and profound insights into the biological components of both sickness and health. The other development concerns the penetrating effects of the Internet and new social media, which have revolutionized the way we communicate and interact with one another.

When it comes to genetics and genomics, one of the major underlying questions for the cultural and social sciences has been the change, actual or potential, which this scientific development brings to different cultures and societies (see, for example, Clark et al. 2010; Rose 2007; Petersen & Bunton 2002; Atkinson, Glasner & Greenslade 2007). More specifically, the novel insights into the human body generated by genetics and genomics are seen as producing new social formations and social identities among different societal groups (Atkinson & Glasner 2007: 1). It is not hard, according to an early prediction made by the anthropologist Paul Rabinow about these new social formations, 'to imagine groups formed around the chromosome 17, locus 16, 256, site 654, 376 allele variant with a guanine substation' (Rabinow 1996: 102). One prominent example of this development can be found in relation to Huntington's disease, a lethal and incurable genetic disease that affects the brain, and the work of the Hereditary Disease Foundation, founded by the American psychologist Milton Wexler. Milton Wexler, whose wife was diagnosed with Huntington's disease, took several initiatives

as a relative and layman to set up interdisciplinary scientific workshops with biomedical researchers as a strategy to promote new and innovative research on the disease, and the foundation is today one of the major financial benefactors of research on Huntington's disease (Wexler 1995). Moreover, genetic knowledge and information on the human body is also seen as influencing human self-understanding and identity, giving rise to what sociologists Carlos Novas and Nikolas Rose (2000) have described as a 'somatic individuality', where we come to experience and understand ourselves increasingly through biology and the different biological processes that underpin the function of our bodies (ibid. 487).

In order, then, to capture how the interplay between biomedical knowledge, culture, and society is manifested in a range of struggles over individual identity, demands for recognition, and access to knowledge, as well as claims for expertise, scholars working in the cultural and social sciences have tried conceptualizing these new social formations in terms of biosociality and biological or genetic citizenship (Rose 2007: 131–54; Rose & Novas 2005: 439–63; Heath, Rapp & Taussig 2004: 152; Rabinow 1996), taking, say, biosociality as an analytical framework with which to understand how new collectives, joined together by shared biomedical traits, now appear in the intersections between science, the economy, and society at large (Brekke & Sirnes 2011: 349).

However, parallel to this biomedical development, digital society has come to stay in the wake of a steady conversion of analogue information into binary code. This process has progressed to the extent that a vast range of information can be obtained by using the same device, be it a stationary computer, a digital television, or a mobile phone (Miller 2011: 15, 73–4; Manovich 2001: 25, 45–8). In addition, as the recent events in the Middle East illustrate, the Internet and the new social media can be instrumental in accomplishing major social and political changes.

The digitalization of society has left its mark on biomedicine, of course. From a scientific point of view, bioinformatics came about as a way to handle, using digitalization, the immense quantities of information generated by the sequencing of the human genome. Moreover, the opportunities generated by a digital society constitute the basis upon which companies offering direct-to-consumer genetic tests sell genetic tests directly to the public. However, considering the growing importance of the Internet and new social media in realizing social and political change in other cultural and societal contexts, the effect of

the digital society on new social formations and identities in relation to genetics and genomics is still an issue that remains to be investigated. Specifically, the role of the Internet and new social media in the everyday lives of those suffering from genetic diseases is a topic that is still a comparatively unexplored area for scholars in the social and cultural sciences.

Consequently, this essay aims to investigate the role of the Internet in the generation of social formations and identities in relation to genetics. What kind of social formations can be discerned on the Internet? What are the differences between these formations and those which exist outside the Internet? What kind of identities can be observed? What roles do the Internet and new social media play and what are the specific aspects of the Internet and new social media that contribute to the creation of new social formations and identities?

An ethnographic approach, directed at the role of Internet and new social media (for which read Facebook) for individuals affected by Huntington's disease, was employed in order to fulfil this aim.[1] The choice has fallen on Huntington's disease as an illustrative case because it represents a large group of devastating chronic diseases for which there is currently no cure, following a well-established research strategy by which Huntington's disease is taken as the 'model disease' when it comes to social and ethical issues, and particularly with regards to predictive genetic testing, for it was among the first genetic diseases where this form of genetic testing became available for individuals at risk (Tibben 2007; Brouver-Dudokdewit et al. 2002). Moreover, although it affects few individuals, Huntington's disease has also come to function as a 'model disease' for the medical sciences, as it is caused by a mutation in a known gene but shares clinical features with more common brain disorders such as Alzheimer's disease and Parkinson's disease, for which there are no clear explanations as to their causes.

The disposition is as follows. First, I will give an account of Huntington's disease and its symptoms. In order to cope with their situation, affected individuals came together in a local support group in which they obtained support and exchanged practical solutions for handling daily life. The activities and the community that arose around Huntington's disease within the local support group studied here were considered using Paul Rabinow's concept of biosociality. However, the ethnographic material at hand points to differences between the activities that took place within this local support group

and the activities that took place online in the new social media. In order then to account for these differences, I suggest differentiating between two forms of biosociality—'practical biosociality' and 'online biosociality'—which differ both in their content and range of action, and look at each in turn, starting with practical biosociality among the local support group. The focus of this group's activities was upon sharing practical solutions and support in conjunction to care-giving rather than broader issues such as direct involvement in Huntington's disease-related research and the formation of new social identities. I then turn to online biosociality, with affected individuals able to use social media (Facebook) to connect with a far greater number of affected individuals than was the case for the local support group—an ability to connect that implied the creation of novel identities, mainly among those who have been found to be gene carriers for the mutated gene that gives rise to the disease: a situation in which they do not show clear signs and symptoms of Huntington's disease.

In the concluding section, I relate this online biosociality and its characteristics to the notion of spatiality by proposing that the role of the Internet and new social media for genetics and genomics should be understood in terms of a dialectic relationship between social and spatial aspects. The question of spatiality is a widely investigated theme within ethnology,[2] yet the spatial aspects of the Internet and the use of new social media in everyday life have been subject to ethnological investigations to the same extent (for one example, see Löfgren & Wikdahl 1999). In focussing on the dialectics between the spatial and the social in conjunction with Internet, I draw on the sociologist Henri Lefebvre's (1991) concept of social space, as well as the philosophers Giles Deleuze and Félix Guattari's (2004) rhizome metaphor, and notions derived from geographers David Harvey (1990) and Edward Soja (1996).

Huntington's disease

Huntington's disease is caused by a mutation in a single gene and the pattern of inheritance is autosomal dominant, which means that a child of an affected parent has a 50 per cent risk of inheriting the mutated gene (HDCRG 1993). The mutation is fully penetrant, indicating that its presence always leads to the disease. The disease is characterized by a combination of neurological, psychiatric, and cognitive symptoms. In general, the onset of the neurological symptoms is between 35 and

45 years of age, and the progression of the disease always leads to death within 15–20 years after the onset of the neurological symptoms (Ross & Tabrizi 2011). No disease-modifying treatment or cure exists.

The formal clinical diagnosis is based on the presence of unequivocal signs of neurological dysfunction (HSG 1996). These neurological symptoms include disturbances of mainly involuntary movements, where the control of voluntary movements becomes more and more difficult as the disease progresses, finally being impossible to coordinate for the affected individual. The psychiatric symptoms of Huntington's disease, which most often are present before the onset of the neurological symptoms, include personality change, irritability, and aggressive behaviour, as well as depression (Johnson et al. 2007; Julien et al. 2007). Huntington's disease also includes cognitive disturbances including attention deficit, which progresses to dementia in the later stages of the disease (Stout et al. 2010).

Practical biosociality as a response

The discovery at the beginning of the 1990s of the gene that causes Huntington's disease paved the way for predictive genetic testing. Being at risk, or being a gene carrier for the mutated gene, is indeed a difficult existential situation which leaves the individual living in a border zone between sickness and health (Hagen 2011; Konrad 2005).

Jimmy's mother is sick with Huntington's disease and he decided, together with his two sisters, to go through with predictive testing to determine their genetic status. His decision was taken in close conjunction with his younger sister, who lives in the same city, and with whom he became very close during this period of their lives. Jimmy's predictive test turned out to be negative, which means that he is not carrying the mutated gene, but his thoughts about the difficulties if his sister (who, together with their older sister, also turned out not have the mutated gene) had tested positive illustrates the influence of the disease on the social relations within the family:

> Jimmy: I went around and thought about how I should behave towards her. If she had ended up a carrier and me a non-carrier. Well, how could I look her in the eye after that? How could I— how could I tell her any good news after that? How would I act? You know, there were a lot of thoughts about how to behave towards—

> towards a person who is affected by [Huntington's disease], because you'll automatically feel sorry for that person[3].

Jimmy's experience of going through genetic testing for the disease indicates both the complexity, as well as the uniqueness, of the challenges that face individuals who are affected. One of these challenges concerns the ability to share experiences and thoughts about the disease with people who can understand the complexities that arise in relation to Huntington's disease. Thoughts and feelings about the disease and personal circumstances are hard to share even with family members. Patricia is in her mid-thirties and has found out, through predictive genetic testing, that she carries the mutated gene. This means that she will inevitably fall ill, but for the time being she does not have any visible symptoms and is thus a so-called pre-symptomatic patient. In her interview she pointed out the difficulties of trying to put words to her experiences for those who have not come in contact with the disease before:

> Patricia: It's just that I never know how— because the hardest part is the beginning 'cause [Huntington's disease] covers so much. So the hardest part is to start explaining it to somebody who doesn't know anything about it, because I know it's really complicated at the beginning.

One important strategy for overcoming these everyday difficulties is the mutual support offered by support groups where affected families can share their experiences. Both Jimmy and Patricia had been active in one of these groups which, as Jimmy noted, offered individuals both advice and solutions regarding practical difficulties encountered in daily life:

> Jimmy: We're all in the same boat. And come to hear what kind of problems the others have had. What they have succeeded with and what they have not succeeded with. If there's a problem, you can discuss it because there's bound to be someone else who has faced the same kind of problem. Somebody who can help me get around that problem.

As noted already in the introduction, much attention in the cultural and social sciences has been directed towards mapping how scientific

developments in genetics and genomics shape both individual and collective practices. Here, Paul Rabinow's notion of biosociality constitutes an effort on the part of these sciences to conceptualize how the scientific developments within the biomedical sciences may change existing cultural, social, economic, ethical, and political practices. Moreover, such concepts as biological and genetic citizenship are intended to capture how individuals shape their relations with biomedical science, the state, and its institutions around a shared genetic status (Gibbon & Novas 2008: 1–2; Fitzgerald 2008; Rose 2007: 134; Heath, Rapp & Taussig 2004: 152).

However, the activities of the local support group that Jimmy and Patricia attended were focused upon the difficulties of living day to day with Huntington's disease, where issues such as mutual support, practical solutions, and help navigating the bureaucracy of the welfare state were the among the main concerns for those individuals who attended group meetings. This is in line with the findings of other ethnographic investigations conducted in the context of neurodegenerative diseases. For example, the anthropologists Carole Browner and H. Mabel Preloran's (2010) ethnographic studies of a number of neurodegenerative diseases, including Huntington's disease, show that the most consequential aspect was the 'everyday burden of living with neurodegenerative diseases' (ibid. 112).

The importance of biomedical research for hopes for a cure, or at least the alleviation of symptoms, was of course a topic that came up during the interviews, but, nevertheless, the participants' greatest concerns were practical issues in their everyday lives—not active involvement in biomedical research on Huntington's disease, or viewing themselves in terms of a 'somatic individuality'. As such, the activities of this local support group show greater affinity with older forms of socialization among individuals affected by genetic diseases, which, according to the anthropologist Sahra Gibbon and the sociologist Carlos Novas, (2008) 'was mostly concentrated on the provision of social and economic support to affected individuals and families, as well as the amelioration of clinical care given that there was little that could be done to treat these kinds of diseases' (ibid. 2). Nevertheless, these individuals came together and formed a community on the basis of Huntington's disease and a daily life very much influenced by the disease, something which certainly echoes the social formations centred on genetics and biomedicine suggested by Paul Rabinow. However, due to the focus upon

practical issues rather than the broader issues of biomedical research and the formation of a disease identity, I would argue that the biosociality concept needs to be differentiated according to its actual content and the range of activities that take place between different actors and in different locations within society. Consequently, I would suggest that the activities of this local support group should be specified in terms of a practical biosociality, which, as I will show, differs from the social constellations and activities to be observed in Internet-based groups.

The practical biosociality offered by local support groups might not be the optimal solution for many individuals who in various ways are affected by Huntington's disease. Carolyn, whose husband has the disease, was part of the same local support as Patricia and Jimmy for some time. For her, the practical biosociality offered by the group meant a great deal for her in overcoming the difficulties that both she and her family were faced with when her husband was diagnosed, but during the interview she recalls what happened when the group was joined by two young adults who had undergone predictive genetic testing for Huntington's disease:

> Carolyn: One time, there were a couple of young people who'd just got tested and started to attend the meetings, and then they had to listen to the older people who talked about all the problems with their family members [who were sick with Huntington's disease]. They never came back, those young girls; one of them was newly tested, and the other one had taken the test a few years back, so she was a bit further on in her process. But it's not really constructive.

And even though Patricia readily acknowledged the importance of the support offered by the group, she nevertheless felt that she needed something different:

> Patricia: I think it has been good, it has been useful-- but I wish there'd have been more young people, of course. I feel actually that I don't need a sort of family— but rather a group for myself. For people in my own situation, that is.

As a gene carrier who at the time did not have any neurological symptoms, Patricia's situation differed from many of those who were part of the support group: most of them were either family members or had

tested negative for the mutated gene. The chances of Patricia finding others in the same situation as her were limited due to the rarity of Huntington's disease—in Sweden, there are about 1,000 individuals who are sick with the disease. Thus one alternative was to find people who shared her situation using online social networks such as Facebook.[4]

Online biosociality through Facebook

Online social networking is currently revolutionizing the way people socialize, identify potential collaborators or friends, communicate with one another, and identify relevant information (Eysenbach 2008). It is therefore not entirely surprising that online social media have emerged as important channels for people with common medical conditions to communicate with one another. Sites such as Facebook can serve as patient forums, in particular for adolescents, where they can express and compare their experiences, and give and receive empathy (Farmer et al. 2009; Madan et al. 2011).

Of the participants in the present study, it was Patricia who had made use of the new social media (Facebook) in order to get in touch with other affected individuals. She started to use the Internet, initially by means of her own homepage, to express her thoughts and feelings when she found out she carried the mutant gene. The online response from others who were affected was not only appreciative, it gave her an increased sense of affinity with these individuals:

> Patricia: Yes, I also felt an affinity. I became really happy. Of course! I mean, partly because there were people out there who appreciated what I've done [setting up the homepage], and partly because they also gave me so much. When they wrote back [by email] and told a little about their own situation ... it gave me so much in return, because it gave me the energy to carry on and to make something positive out of it.

After this initial online presence through her own webpage, Patricia then came in contact with Facebook after meeting individuals who were in the same situation as her in London. The experiences she had had with her homepage were repeated, even redoubled, when her initial contacts on Facebook grew rapidly into a whole network of people who in various ways were affected by the disease:

> Patricia: Mostly, I have to say, people just found you. It was— and then it just became more and more, so to speak. I must have had something on Facebook that told, something with Huntington, you know something that made people get in touch by mail, asking in what way I was affected. And then that [person]—you know that's the advantage with Facebook—has another friend, who has another friend, who has another friend. And then the whole thing takes off, so to speak. Suddenly in no time at all you've got a whole mass of people [as friends on Facebook]. But in the beginning no one in Sweden.
> Niclas: Not?
> Patricia: No, they were mostly in Europe and the US.
> Niclas: How did you feel about that?
> Patricia: I thought it was really cool. And mostly, all of a sudden, going from, in the beginning it was only me who was affected, and then I made a bigger thing about it through my homepage and felt, Oh, there's more than me who's affected in Sweden. And all of a sudden there were people in Europe and in the whole world who were affected. Because you don't think like that in the beginning, like there's people all over who have this, who maybe face the same kind of problems.

The contacts that she made and maintained through her homepage and subsequently on Facebook became important in her everyday life by dint of their reciprocity. In the interview, Patricia recollected a situation when the consequences of the disease became apparent and very emotional for her. In this difficult situation, she went online in order to express her emotions and to find support:

> Patricia: Damn this disease! It's so devastating, that it can destroy people's lives the way it's doing, but that's the first time I really felt it, and, as I told you, I have many friends on Facebook who are engaged in Huntington's disease and that day I wrote [on Facebook], 'Damn Huntington'!

Her contacts gave her a sense of belonging, as well as the energy to cope with the fact that she was carrying the mutated gene. As Lijun Tang (2010: 616) has noted, online communities often consist of like-minded people who socialize around common interests, relating to

one another through a defined set of interests or identities. Moreover, previous research also shows that online support might serve as a compliment, or even as an alternative, to the mutual assistance and support offered by regular support groups (Braithwaite, Waldron & Finn 1999; Nicholas et al. 2009; Leimeister et al. 2008; Coulson, Buchanan & Aubeeluck 2007; Finn 1999).

There were of course many similarities between the face-to-face interaction in the local support group and the kind of interaction that takes place upon Facebook. Needless to say, in both contexts the individuals who were affected by Huntington's disease were able to connect with others who were in the same situation, and to obtain and give support. And, just as in face-to-face encounters and relationships, conflicts could also erupt among those who were active on Facebook forums relating to the disease; conflicts that could sometimes result in heated discussions within the group. However, the crucial difference was that the interactions on Facebook transgressed both temporal and geographical limits in what David Harvey (1990) refers to as a 'compression of our spatial and temporal worlds' (ibid. 240). As noted by the media and communication scholars Graham Meikle and Sherman Young (2012: 61, 62), social media such as Facebook permit individuals to view and traverse the connections made by others in order to find and connect with other individuals who share their interests: online communities emerge through interaction in the network as users build up a presentation of self that allows others to locate them within shared cultural contexts.

These two intrinsic features of Facebook—the compression of time and space, and networked interactions—provided Patricia with contacts far beyond her immediate social network and the local support group. Through her Facebook profile, individuals who in various ways shared her situation could easily locate her. Her list of contacts grew rapidly as soon as she began to use Facebook, and through this online biosociality she came to experience a sense of belonging that went far beyond what she had experienced before; something that came to play an important role in her everyday life, especially at times when she needed emotional support. Moreover, these online interactions with other affected individuals also gave her a new perspective upon her situation as a carrier of the mutated gene.

Given the networked interaction on Facebook and the service's compression of time and space, I would like to suggest the term online

biosociality as a way to capture how the Internet and new social media effect new social formations in relation to genetics and genomics. Such online biosociality constitutes an enhancement of what Nikolas Rose (2007: 134, 135) has called the collectivizing moment of biosociality, by which new social formations are assembled around a shared genetic status. Yet, I would like to stress the grass-roots character of this online biosociality, which, due to the networked interactions on Facebook, was established 'outside' the more formal setting of a patient organization or a local support group. In fact, in relation to previous research, the most striking feature of this online biosociality is the absence of any form of formal setting through which these interactions were established. However, as I will show in the concluding section, the basis for this type of biosociality is not to be understood in terms of social aspects, but rather of a dialectic relationship between social and spatial aspects. These distinguishing aspects become even more relevant in relation to another issue that was evident in Patricia's accounts, namely in relation to what Sahra Gibbon and Carlos Novas (2008) term 'emergent identity practices' (ibid. 1). Facebook is not only a source of mutual support; it is also a space wherein new identities are formed in relation to genetics and genomics.

Facebook and the formation of the HD+ identity

Carlos Novas and Nikolas Rose (2005) argue that the interplay of increased genetic knowledge, genetic risk, and identity will give rise to a 'somatic individuality' in which 'genetic forms of reasoning, explanation, prediction and treatment of human individuals, families or groups—find their place within this wider array of ways of thinking about and acting upon human individuality in "bodily" terms' (ibid. 491). Likewise, developments within the neurosciences are thought to herald the same kind of impact in relation to human mental abilities. Here, increased biological knowledge about the human brain might generate what Nikolas Rose (2007) has described as neurochemical selves, as various human mental abilities that were previously understood in terms of various psychological frameworks are 'mapped upon the body itself, or one particular organ of the body—the brain' (ibid. 188). Moreover, the impact of science upon individual and collective identities is not only to be seen in relation to scientific knowledge as such, but also to an increased usage of visualization techniques such as MRI (Joyce 2010: 198).

The issue of identity is indeed a prominent aspect of Huntington's disease (even though the ethnographic material conveys the complexity that arises due to the multifaceted symptoms of the disease), most obviously in relation to the various psychiatric and cognitive symptoms that made the sick individual become 'somebody else'. This transition—this loss of self—was one of the most difficult aspects of the disease to cope with for families and friends. In the interview with Elizabeth, whose husband Brian was diagnosed with the disease, she stated how painful this kind of transition is for all those who are affected:

> Elizabeth: While I'm always searching for my old Brian ... In everything, well that's what I'm still doing, even though I know that he's gone for ever, I'm still trying to revive this, his— if I should say, normal reactions or viewpoints. And that, that I've been struggling a lot with— a lot with, to keep him from disappearing in that way.

However, some of the affected individuals stressed the fact that they remained the same, despite gradually losing their physical abilities to the neurological manifestations of Huntington's disease. Luke, who is a competitive-minded person and used to swim competitively before the onset of the disease, pointed out in the interview that he had retained his sense of self despite his bodily transition:

> Luke: I'm still the same ... I never give up—

Yet, for those who chose to go through predictive genetic testing, the result of the test seemed to have more of an impact on their sense of identity. Jimmy, who found out that he did not carry the mutated gene, said that the test result did change the way he viewed himself:

> Niclas: Is there another Jimmy now [after the test result]?
> Jimmy: I think so— it's easier maybe to ask others about that, but I think— I think I'm more positive to most things. Eh— mostly the aspect of being more positive, that you— you see so many things in a totally different way. Things have opened up—

For Jimmy, the result of the predictive genetic test meant that he went from being at risk of Huntington's disease to being out of danger, which allowed him to foresee a future without the disease hanging

over him. This knowledge gave him a completely different perspective on life—for example, on whether to start a family with his girlfriend. For those who find out that they are carrying the mutated gene, the situation is very different, as they now face a future of certain illness, even though such signs and symptoms of the disease that there may be are vague. Previous research among individuals who have undergone predictive genetic testing for Huntington's disease suggests that they are situated in a border zone between health and illness (Hagen 2011). Consequently, from a cultural perspective, those who carry the mutated gene can be seen as being situated between the two cultural classifications of normality and abnormality.

As medicine increasingly aims to investigate and act on disease on the molecular level of the body, it is on the same level that efforts to predict and cure disease before the symptoms become apparent will be increasingly concentrated, and as such it will be incorporated in our everyday experience. Arguably, this change cannot come without complications for those affected by the change. From their research on genetic haemochromatosis, a blood disorder, the sociologists Aditya Bharadwaj and Paul Atkinson and the clinical geneticist Angus Clarke (2007), argue that this shift towards the non-tangible level of the human body concerns not only various forms of medical expertise (who can 'find themselves expanding or contesting the boundaries of disease classifications and criteria'), but also patients who might also 'be engaged in exploring and contesting such boundaries', and they go on to state that 'when professional classifications are uncertain and shifting, lay nosographies of genetic disorders are implicated in the process of diagnostic inference' (ibid. 123). The anthropologist Monica Konrad (2005: 82) goes even further when she contends that the very notion of a pre-symptomatic patient radically challenges the Western biomedical notion of the patient as someone necessarily isomorphic with a presenting illness or cluster of detectable symptoms.

Currently, an individual who is found to carry the mutated gene for Huntington's disease receives a formal diagnosis when he or she presents clear neurological symptoms in the form of choreatic movements. Until then, the individual is considered a gene carrier or a pre-symptomatic patient, even though the individual might present various forms of psychiatric symptom that are equally symptomatic of Huntington's disease, albeit in a more diffuse and subtle way than the neurological symptoms. The question of when an individual is

considered to be sick with Huntington's disease is something Patricia returned to frequently when talking about her own situation as a gene carrier. Here she favoured the use of the term HD+, as it provided a better description of her situation than terms such as gene carrier or pre-symptomatic patient:

> Patricia: I mean, it does matter what people call you. There again, it depends on what you interpret as sick or not. I mean, gene carrier, it sort of becomes, Ok— it doesn't feel like it means anything. More of something that might or might not happen. ... But HD+ it's more like— I think it proclaims that, OK, you have a disease.

This formation of a disease identity, however, is a process that naturally did not occur in isolation, but rather took place as a collective process on Facebook:

> Patricia: Yes, it does. Experience and info. Which makes me understand. You know, there it is again, it's difficult to think when it's only you, the same thing goes for the doctors who, when they sit down and think, don't really understand it either.
> Niclas: Is it an insight that grows, then? That you discuss these things on Facebook?
> Patricia: You know, it can be that somebody posts something like either a thought about how something might be in the future, or something about an ailment or symptom, or something that they might have at the moment. Or something about their family member, or maybe they post a question if there is someone who has some sort of experience of whether it can be like this. So, it's many pieces— even though they might have doctors, they don't get the answers from them. Maybe they got from the doctors that [a certain sign or symptom] it has nothing to do with Huntington's. And then when they post on Facebook, they get tons of answers, like, my husband has that [symptom] as well, my wife and daughter have the same [symptoms], and all of a sudden you get another picture and think, Alright, of course there's a connection, for us it's so obvious in a way that it's not for doctors or geneticists.

Apart from offering different forms of social support, then, exchanges about the lived experience of Huntington's disease on Facebook become

an important part in the generation of the HD+ disease identity among affected individuals. The main implication of the HD+ designation is that you, as a gene carrier, are to be considered sick with Huntington's disease despite an absence of gross neurological pathology. As such, the HD+ designation also constitutes an example of the lay nosographies observed in the context of genetic haemochromatosis, where a social disease identity was formed that differs from the view currently taken by the medical system (Bharadwaj, Atkinson & Clarke 2007: 123). From a cultural perspective, however, the HD+ identity can be seen as a way to handle a complex and difficult situation, where affected individuals are stranded between normality and abnormality.

The ethnographic material indicates that this online biosociality is crucial for the formation of the HD+ identity. Once again, it was a compression of time and space, taken with the possibility for networked interactions, which provided Patricia with a number of lived experiences of Huntington's disease that stretched far beyond her immediate social network, including the local support group. In other words, one crucial component in the formation of the HD+ disease identity was the type of online biosociality that Patricia became part of through Facebook. The ability of Facebook (and the Internet per se) to compress time and space, as well as offering networked interaction to its users, points to the need to consider spatiality if one is to understand the role of the Internet and new social media in relation to genetics and genomics. And in order to achieve a more comprehensive understanding of these spatial aspects, it is worthwhile considering Facebook as a form of social space whose intrinsic properties can be understood using Giles Deleuze and Félix Guattari's (2004) rhizome metaphor. It is also these intrinsic properties that give rise to differences and potential transformations that might have an impact on those affected by disease and who take part in online biosociality of the kind examined here.

Facebook, a rhizomic social space

The ethnographic material thus indicates that the role of the Internet in relation to genetics is dependent on space, and specifically on the intrinsic spatiality of the Internet. It is the nature of the Internet's virtual space that makes the kind of online biosociality discussed here possible. This importance of space points towards the inseparability and interdependence of the spatial and social realms of human life (Soja 1996).

David Harvey (1990), who singles out time–space compression as one of the hallmarks of the capitalist society, also posits the inseparability of spatial and social practices, where 'spatial practices derive their efficacy in social life only through the structure of social relations within which they come into play' (ibid. 222–3). This, naturally enough, raises the question of what kind of spatial formation we encounter in conjunction to the Internet and Facebook. What are its properties? And what kind of transformations might these properties give rise to?

Several authors describe the spatial formation of the Internet by invoking Deleuze and Guattari's (2004) rhizome metaphor (Miller 2011: 26–9; Hess 2008; Robinson & Maguire 2010; Clothier 2005: 49). Deleuze and Guattari (2004) describe a general form of organization that is not based on a hierarchical structure—such as characterizes a tree and its root system—but rather on a network, and to that end they use the metaphor of the rhizome. The rhizome 'assumes very diverse forms, from ramified surface extension in all directions to concretion in bulbs and tubers' (ibid. 7). The rhizome connects any point to any point (unlike the tree and root system, which plots a point and fixes an order). It is open and connectable in all of its dimensions: detachable, reversible, and apt to constant modification. It is, moreover, to be seen in terms of its multiplicity, for it is neither a collection of individual things nor one large entity, but is instead composed of dimensions and lines of connection (ibid. 7–23; Miller 2011: 26–7).

The principle of connection is fairly easily established with the metaphor of the rhizome, as the open and connectable element can be seen as one of the chief characteristics of the Internet's structure. For example, one can connect to the Internet from any point, and traverse it freely from one hyperlink to the next in seemingly random ways, something that implies that the Internet is composed of dimensions and lines of connectivity rather than a hierarchical tree structure. The supposedly chaotic networked structure of the Internet means that there is no real centre, and the web is fully able to sustain breakages without much effect on its function (Miller 2011: 27; Al-Zobaidi 2009: 306).

I have argued that time–space compression and networked interactions are intrinsic to Facebook, and it is these two features that give rise to an online biosociality whose main feature is an enhanced collectivizing moment, bringing individuals together for mutual support and, by extension, the formation of the HD+ identity. If it is accepted that spatiality is a product of social relations, just as social relations are a prod-

uct of spatial formations, the ethnographic material can then be taken to indicate that there is a dialectic relationship between the rhizomic space of the Internet and the online biosociality offered by Facebook to the likes of Patricia. The French sociologist Henri Lefebvre (1991) conceptualizes this dialectic, and ontological, relationship between the social and the spatial with the term *social space*. According to Lefebvre, a social space is not to be seen as one thing among others, or indeed as a product among other products, but rather as subsuming the things produced, encompassing their interrelationships in their 'coexistence and simultaneity' (ibid. 73); and albeit this social space has 'nothing of a "subject" about it, yet it acts like a subject in that it transports and maintains specific social relations, dissolves others and stands opposed to yet others' (ibid. 50). New social media, such as Facebook, exemplify Lefebvre's notion of a social space within which the social and the spatial co-exist. This leaves Facebook to be understood as a social space, which, due to its rhizomic nature, enables individuals affected by Huntington's disease to form an online biosociality, despite their limited numbers. In other words, it is the underlying dialectic relationship between spatiality and sociality that forms the basis for those aspects of biosociality that I have been investigating here. Moreover, the same dialectic enables online biosociality to be established through an informal, grass-roots movement, outside the more formal settings of patient organizations and the health-care system.

There is another side to this rhizomic social space that needs to be acknowledged, however; one that casts informal online biosociality in a more ambivalent light. Here one must bear in mind yet another characteristic of the rhizome: implicit in a rhizomic organization is the transformative potential that resides in its multiplicity, and which operates by 'variation, expansion, conquest, capture, offshoots', where every dimensional change implies a potential metamorphosis in nature as well (Deleuze & Guattari 2004: 23). The sociologist Vincent Miller (2011: 28) exemplifies this transformative potential by drawing an analogy with the impact of the Internet on printed newspapers, which, while they have been transformed by the arrival of Internet, have in turn transformed the Internet—newspaper sites being among the most prominent sites on the web.

Likewise, Facebook's rhizomic properties harbour the potential to transform the essence of the social relations that arise from the constitutive, dialectic relationship between the social and the spatial. In

relation to online biosociality, the transformative potential of the rhizome becomes an issue in the friendships—and the nature of friendship—on Facebook. As noted by Graham Meikle and Sherman Young (2012), friendship, which is an elusive concept at the best of times, even outside the new social media, becomes something of a metaphor when it comes to Facebook, meaning only 'other Facebook users with whom I am connected on Facebook': many users are likely to have numerous Facebook friends whom they have never met face to face in real life, and with whom they only interact in and through this social space (ibid. 74–5)

The fact of being merely connected by being Facebook friends became very obvious in some of Patricia's thoughts on her future. In the interview she acknowledged that the online biosociality of which she is part might not last forever:

> Patricia: If you're to be realistic, you know the reality of how everything will be; I will not be able to communicate, you know through social, Facebook, homepage, chat, etc. And then that contact breaks off. That's the way things are. It disappears, and then you have your friends in the real world, so to speak.

The very same rhizomic properties that enabled Patricia so easily to become part of this online biosociality on Facebook might just as easily be lost if she loses her ability to connect and interact through the Internet. I would argue that this implies there is a transformation in just how far friendship can reach within a social space such as Facebook, something that becomes very obvious—very real—in the context of Huntington's disease, and indeed illness in general. It is in the nature of a rhizomic social space such as Facebook to impose limits on the prospect of turning online biosociality into a practical biosociality of the kind so evident among the local support group studied. The question of what happens the day you become too sick to communicate with others reveals an elusive feature of the rhizomic social space and the online biosociality discussed here. In the light of a rapid expansion of Facebook and other new social media, this elusiveness might well become an important factor as we continue to investigate their role in relation to genetics and genomics, and to diseases in general.

In this essay I have examined the role of the Internet and the new social media in generating social formations and identities in terms of

genetics. The analysis of the ethnographic material indicates that one of the primary roles of the Internet and new social media could be connected to their spatiality, and by combining concepts derived from both anthropology and geography, the role of the Internet was seen in terms of an establishment of a rhizomic social space (Facebook) where networked interactions can take place among individuals affected by Huntington's disease. Drawing upon Paul Rabinow's concept of biosociality, these networked interactions are seen in terms of an online biosociality that grew up outside more formal organizations as a form of grass-root movement. Being part of this online biosociality enables affected individuals to form a large number of online friends with whom they can communicate on issues related to various aspects of a disease, for example the experience of being ill with Huntington's disease despite having no neurological symptoms. Moreover, the ethnographic material also indicated that this online biosociality also enabled certain individuals to construct a novel identity, HD+, that amounted to a layman's alternative to the current diagnostic criteria for Huntington's disease. However, also intrinsic to this rhizomic social space is its transformative potential for online friendships and the like, an effect likely to be seen in how far online friendships truly extend when the affected individuals become incapable of remaining part of this online biosociality.

Thus through its spatial features, the Internet presents novel opportunities to come together in various sorts of online community, not only for individuals with rare genetic diseases but also those with common ailments. The breakthrough and spread of new social media such as Facebook enhance this possibility even further, as the rhizomic properties of the Internet enable affected individuals to establish online communities that do not require the development and maintenance of digital services, the result of grass-roots movements that exist outside the formal settings of patient organizations and the health-care system. Indeed, one crucial question concerns the relationship, both now and in the future, between these online movements, regular patient organizations, and the health-care system. In the context of Huntington's disease, novel disease identities have been formed among affected individuals that partly endorse an alternative understanding of the current diagnostic criteria employed within the health-care system. It remains to be seen if these online movements extend their opinions and influence beyond Facebook's social space. Similarly, when

it comes to the kind of online friendships seen in the ethnographic material, only time will tell what their possibilities and limitations will be. As our everyday life becomes a digital everyday life, these and other issues become central when investigating the impact of genetics and genomics on our culture and our society.

Notes

1 The ethnographic material of this article was obtained in a study conducted in southern Sweden in 2009–2010 with individuals affected by Huntington's disease in various ways. Semi-structured interviews were conducted with eleven individuals in affected families, lasting between 90 and 150 minutes, and in a place of the interviewees' choice. An interview guide was employed, but used in a flexible way so the interviewees could go into various aspects regarding their experience of Huntington's disease on their own terms. All interviews were recorded and subsequently transcribed verbatim, each transcript then being read for a number of identified themes. All quotations from the interviews given here are rendered in similarly colloquial English. The study was conducted within the Cultural Study Research Team of Lund University's Basal Ganglia Disorders Linnaean Consortium (Bagadilico), <http://www.med.lu.se/Bagadilico>, an interdisciplinary research consortium focusing on Parkinson's and Huntington's diseases. The study was approved by the regional ethical committee at Lund University.

2 Ethnological research on space and spatiality includes research that investigates the representation of space through cartographic visualizations (Idvall 2000); the relationship between the body and the physical space of mental asylums (Jönsson 1998); the relationship between space and objects within different commercial settings (Ottoson 2008); the experience of asthma in relation to physical spaces (Hansson 2007); and the relationship between suburban space and identity (Ristilammi 1994).

3 All the names of the respondents in the study have been anonymized.

4 Facebook was started in 2004 by Mark Zuckerberg and others to provide Harvard students with an online meeting place. Since then the online networking site has seen a rapid explosion in terms of active users, and according to internal corporate statistics has one billion million active users, with more than 50 per cent accessing the site every day (<http://newsroom.fb.com/News/One-Billion-People-on-Facebook-1c9.aspx>, accessed 16 October 2012) making it the most frequented social network site worldwide (Madan et al. 2011: 678).

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Paper IV

Culture Unbound
Journal of Current Cultural Research

For Better or for Worse: Lifeworld, System and Family Caregiving for a Chronic Genetic Disease

By Niclas Hagen, Susanne Lundin, Tom O'Dell & Åsa Petersén

Abstract

Modernity has meant a cultural and social differentiation within the western society, which, according to Jürgen Habermas' theory on communication, can be seen as a division between different forms of actions that takes place in different realms of the society. By combining Habermas' notions of lifeworld and system with Arthur Frank's analysis of stories as a way to experience illness, the article performs a cultural analysis of the meeting between families involved in caregiving in relation to Huntington's disease and the Swedish welfare system. The ethnographic material shows how caregiving is given meaning through communicative action and illness stories, which are broken up by an instrumental legal discourse employed by the welfare system. This confrontation between communicative and instrumental action breeds alienation towards the state and the welfare system among the affected families. However, the families are able to empower themselves and confront the system through a hybrid form of action, which combines communicative and instrumental action. As such this hybridity, and the space that opens up on the basis of this hybridity, constitutes an important space within the modern society.

Keywords: Caregiving, lifeworld, system, illness stories, Huntington's disease, hybridity

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Introduction

> Elizabeth: I've struggled a lot with the National Insurance Agency, although they're the ones who have been the most correct in our case. We've had a really good administrator. She demanded millions of papers and sums back and forth. But when we were done with filling in the forms and when she'd been here and made her assessments... So I think she has been very correct. Then we have our local municipality: beneath all criticism. Oh, the welfare administrators in our municipality…we're not friends with each other at all. We're on our third administrator right now. The first one that took care of our case thought that Brian and I should get a divorce, so that the responsibility for Brian's caregiving should rest on them [the municipality and the welfare system]. On one occasion, she said that if we got a divorce, they could take over the caregiving, so that I could continue to live in our house. Yes! It is humiliating, and they don't have empathy!

These words are Elizabeth's, whose husband Brian is affected by Huntington's disease (HD), a rare genetic, chronic and eventually fatal disease that affects the brain.[1] In many ways, their whole life was turned upside down when the disease struck, causing implications, not only in the lives of Brian and Elizabeth, but also of their two children whom Brian and Elizabeth suddenly realized were at risk of inheriting the gene that causes Huntington's disease. The prospect of fighting and handling a chronic disease, for which no cure is available, and which inevitably ends in an early death, was suddenly a fight that might be fought all over again if the children had inherited the HD-gene from their father. Since the time of Brian's diagnosis, one of the children has taken the difficult step to find out, by going through a genetic test, if she, like her father, carries the HD-gene. The test showed that she is not a HD-gene carrier, that is, she will be spared from HD. As for her brother, the answer concerning his fate is still residing within his genetic make-up, as he has not undergone the genetic test that will show whether he is a HD-gene carrier or not.

The chronic and genetic nature of a disease like HD obviously leaves a strong mark on the everyday life of the family, which to a large extent is structured by the needs of the affected individual and the progression of the disease, as well as all the existential aspects that come up in relation to the genetic nature of HD. Yet, the everyday lives of Elizabeth and Brian and other families affected by HD is also very much conditioned by the various forms of assistance they can obtain through the institutions of the Swedish welfare state,[2] a situation in which their circumstances are being subjected to the decision-making of the welfare bureaucracy. Elizabeth's comment above is directed towards a statement made by an administrator working within the local municipality who, when individuals apply for assistance and support from the municipality, assess and make a means test of the caregiving situation. How can we understand the statement made by the administrator above, whose suggestion of a divorce between Elizabeth and Brian seems to be totally out of hand? And how can we understand Elizabeth's anger and feelings about what she perceived to be the administrator's lack of empathy?

To put it differently: What is at stake in the interactions between families who are in the same situation as Elizabeth's and the welfare system? And how can we understand these interactions from a cultural point of view?

The aim of this article is to perform, on the basis of contextually bound empirical material, a cultural analysis of what happens in the interaction between families involved in caregiving and the welfare system. As illustrated by the citation above, these meetings might take the form of a conflict between the family and the system in which different perspectives and actions are contested. More importantly, however, the following analysis aims to problematize the manner in which families confront the demands of the welfare system, and are at times able to develop a space between themselves and that system from which they can act and better confront the difficulties presented to them by Huntington's disease. As such, this analysis provides an account of caregiving for chronic diseases that interprets the interaction between the families and the welfare system in terms of crucial cultural tendencies within modernity and the late modern society. Consequently, this analysis constitutes an additional account in relation to other studies on caregiving, for example performed within nursing studies, which often do not include perspectives derived from the cultural and social sciences (e.g. Skirton et. al. 2010; Williams et. al. 2012).

In order to do this, and following a methodological discussion, the article shall begin by presenting the theoretical framework of the study. The text then proceeds to analyse the different manners in which the affected families and the Swedish welfare apparatus perceive, frame and address Huntington's disease. Next, the article will address the issue of how the affected families empower themselves by creating a space between themselves and the welfare system by adopting the language of the welfare system. This space, from which they act and confront the system, can be characterized as a hybrid form of action and communication that undermines the power of the welfare system. We will end the article with some concluding remarks.

Method

The ethnographic material, which this article is based upon, was obtained as part of a study conducted in southern Sweden 2009-2010 with individuals who are affected by Huntington's disease in various ways. In line with the aim of this article, HD functions as an illustrative case, as it represents a large group of devastating chronic diseases for which there are currently no cures available. The choice of HD as an illustrative case is a well-established research strategy where HD has taken the form of a 'model disease' in relation to social and ethical issues within genetics. This is particularly relevant with regard to predictive genetic testing, as HD was among the first genetic diseases where this form of genetic testing became available for individuals at risk (Brouver-Dudokdewit et. al. 2002; Tibben

2007). Moreover, despite the relatively low number of affected individuals, HD has come to function as a 'model disease' also within the medical sciences. The reason for this is that it is caused by a mutation in a known gene, but shares clinical features with more common brain disorders such as Alzheimer's disease and Parkinson's disease for which there are no clear explanations as to what causes these diseases. Consequently, HD contains features that are unique; the prospect of both parents and children being affected due to the genetic basis of the disease, as well as the possibility to take a predictive genetic test where individuals who are at risk can find out whether they are carrying the mutated HD gene. HD also includes features that are shared with a number of other chronic diseases. In relation to those issues that are investigated in this text, HD affected individuals do require substantial help and assistance in the later stages of the disease. Because of this, the experiences of the HD affected individuals, in relation to the caregiving situation and their interaction with the welfare system, are seen as resembling the experiences made by other individuals who are affected by more common disorders such as Alzheimer's disease and Parkinson's disease. This resemblance is also acknowledged by Williams et al. who, from a perspective of nursing science, investigated family caregiving for HD (Williams et al. 2012:142).

HD has affected all those who have participated in this study in different ways. Participants were recruited through advertisements at various websites aimed for HD affected individuals, as well as through personal visits (made by Hagen who did not know any of the participants before the study took place) and through national and local meetings for HD affected individuals. As HD is both a sensitive and difficult topic for many of those who are affected, the decision was taken on behalf of the authors to let both the sample size and the determination of participants included in the study be based only upon those individuals who came forward as a result of these advertisements and meetings. All of those who came forward and expressed a wish for taking part in the study were sent additional information (including the form for informed consent) and were also given time to further reflect on their participation, as well as the informed consent. By relying upon this approach, the risk for adverse reactions on behalf of the participants due to the sensitive topic were seen as being minimized and all participants were given time to reflect upon their participation. The participants of the study represent *a cross-section* of the various ways individuals can be affected by HD, from individuals with motor symptoms to members of the family. This cross-section provides an opportunity to give a general overview of HD, as well as to provide an investigation that is not biased to a particular feature of HD, such as the issue of predictive genetic testing.

Semi-structured interviews were performed with eleven individuals in families that have been affected by the disease. Hagen performed these interviews. The interviews lasted between 1 hour and 30 minutes and 2 hours and 30 minutes. All interviews were conducted in Swedish and took place at a location of the inter-

viewees' choice. An interview-guide was employed for the interviews, but it was used in a flexible way so the interviewees could go into various aspects regarding their experiences of HD on their own terms. All interviews were recorded by the use of a digital voice recorder, and all interviews were subsequently transcribed *in verbatim* and analyzed by Hagen. The original format was kept in all the translated citations from the interviews used in this article; they have not been altered into grammatically correct English. Moreover, in order to protect the privacy if the participating individuals, the alteration of all names featured in the text was done solely to protect the anonymity of the participating individuals. The analysis took place as follows: First, each manuscript was read several times until a number of themes were identified. Next, the different manuscripts were compared with each other with respect to these themes, and in the third successive step of the analysis, a table of overarching themes was organized, which represented the results of the comparison made in the second stage of the analysis. In the last stage of the analysis, these overarching themes were related to more general cultural and social theoretical frameworks. The regional ethical committee at Lund University approved the study.

The following section provides a presentation of the theoretical framework employed in the article. In order to carry out the ethnographic focus of the article, we intend to use perspectives taken from Jürgen Habermas' account on communicative and instrumental action and combine them with anthropological approaches to understanding stories in relation to illness and disease. This strategy will permit us to situate the experiences made by the affected families within the general cultural and social frameworks of the late modern society.

Communicative Action through Illness Stories: Theoretical Presuppositions and Key Concepts

In his theory on communicative action, Jürgen Habermas represents modern society in terms of an analytical division between lifeworld and system that stand in a tension-like relationship towards each other (Habermas 1987). Both system and lifeworld perform essential functions for society, where the lifeworld acts as a source of legitimate norms and reproduces those cultural and social patterns on which society rests. The modernization of western society gave rise to an increasing societal differentiation that separated sections assigned for the production and distribution of material goods from the contexts of the lifeworld (Crossley 2005: 37-38). These designated sections – the economic system and the administrative system of the state – came to be organized on the basis of instrumental rationality and instrumental action as a way to achieve an increased efficiency in production and distribution of material goods, as well as entitlements provided by the welfare state.[3]

The major difference that separates the lifeworld from the system resides in a disparity between the relation to rationality and the way actions are performed in the lifeworld and the system. Communicative action is founded on mutual understandings and meanings made on the basis of a shared everyday situation. This mutuality enables individuals to harmonize their plan of action in accordance with reaching a common understanding of a situation. The everyday lifeworld can then be regarded as the subjective world that we all experience through our everyday life, but also as a collective cultural and social background from which mutual understandings emerge through communicative action (Habermas 1987: 119-152). Instrumental action that is employed by the system is, on the other hand, oriented towards reaching success and societal goals rather than mutual understanding. The system is to be seen as operating on a *societal level*, detached from individuals who nevertheless make up the smallest units of the system. Money, power, as well as law became the most efficient ways to achieve coordination and integration of the activities within the system. Coordination of system activities through communicative action becomes impracticable as a consequence of an increased modernization and societal differentiation. The classic example of this kind of impersonal integration is of course the economic market where money and such notions as input and output measurements coordinate and steer the activities of the participants who in various ways operate in the economic system (Habermas 1987: 160, 164-166; Habermas 1996: 39-40). Another example of this impersonal integration within the modern society comes in the form of a formal legal discourse that, in a similar fashion to money, regulates and coordinates various forms of actions that hitherto were regulated through informal traditions and customs. The expansion of law in the modern society, the legal regulation of new previously informally regulated cultural and social matters, is defined as a trend towards a 'juridification' by Habermas (Habermas 1987: 357). Communicative and instrumental actions are then to be seen as operating on the basis of two distinct perspectives, as well as operating on two distinct levels of society.

In order to convert Habermas' theoretical insights into operational concepts that work on the micro-level of everyday life, his theory on communicative action needs to be matched with additional accounts taken from ethnology and anthropology. It is in relation to this elaboration that illness stories become relevant, and where the works of, among others, Arthur Frank become important. The concept of illness is employed in medical anthropology as a means of capturing and understanding the experiences of sickness and suffering amongst individuals, but also in conjunction with their families and wider social networks. Subsequently, the concept of illness has come to function as an alternative in relation to biomedical knowledge, which in various ways reconfigures the experience of illness in accordance with an alteration in biological structure and functioning (Kleinman 1988: 2-6). In conjunction to communication and the creation of meaning, Arthur Frank makes the remark that serious illness is, by its very nature, something that

disrupts the flow of everyday life and which prompts all those who are affected to redirect their lives and selves (Frank 1995: 56-59).

This redirection and the formation of new understandings of the self in relation to others occur in response to the disruptive force of illness, through the construction of illness stories. Moreover, Frank also makes a connection between the formation of illness stories and the body. As he argues, the disease-stricken body 'sets in motion the need for new stories when its disease disrupts the old stories'. According to Frank, human communication with the world, and the communion this communication rests on, can analytically be said to begin in the body itself (Frank 1995:1- 2, 50). The telling of these stories is an altogether social activity. Stories are told to others and create, in the process, meaning in relation to the illness. As such, these stories incorporate both the subjective world of the storyteller, as well as the cultural and social frameworks which constitute the lifeworld of all those who formulate the illness story, along with those who respond to it.

The meaning created through the illness story thereby includes aspects that are highly subjective and personal, but also aspects that are derived from cultural frameworks within the lifeworld. The formulation and construction of illness stories can then be understood as *a form of communicative action*, which is formulated on the basis of the diseased-stricken body and through which new meanings are formulated by all those affected in relation to the disruption caused by illness in everyday-life. Communicative action thereby organizes and gives meaning to our experiences of illness. The interaction between the caregiving families and the welfare system can then analytically be interpreted as an interaction between the lifeworld and the system, which incorporates a meeting, as well as movements back and forth, between communicative and instrumental action. Moreover, these theoretical assumptions lead up to a methodological step which, according to Habermas, means that system perspectives 'cannot be adequately dealt with by way of lifeworld analysis undertaken from an internal perspective; it only comes into view when the lifeworld is objectified' (Habermas 1987: 232-233). That is, in order to achieve a systems perspective on the caregiving situation, the analysis will have to operationalize, in the same way as communicative action is made operative through illness narratives, the instrumental rationality used by the welfare system.

The consequences of this methodological step for this analysis are two-fold: First, in order to operationalize a system perspective in our analysis, we will make use of Swedish social welfare laws. These laws constitute the primary medium of instrumental rationality that objectifies the caregiving situation of the HD affected families. The interaction between the HD affected families and the welfare system is essentially then an interaction between these families and the legal discourse that make up Swedish social welfare laws. Second, given this crucial importance of a legal discourse as a form of instrumental action, it follows that interactions between the affected families and various administrators, do not constitute the

actual interactions between the families and the system. These interactions both rely upon and are governed by the legal discourse that specifies what social welfare the affected families are entitled to.

In order to give a fuller understanding of all the aspects that have been outlined in this section, we need to make use of the ethnographic material. In the next section, we will probe more deeply into this dual character of the caregiving, based on the presuppositions and concepts presented in this section. The first part of the next section will investigate caregiving from the perspective of the affected families. Following this, we will turn to the question of what happens when this perspective meets with the perspective taken by the welfare system.

Caregiving and the Affected Families

For the affected families, caregiving is understood and experienced as being tightly embedded in the dramatic and overall change that HD brings to affected families. Previous research on HD has shown that the impact of the disease is to a large degree situated in the family context (Forrest Keenan et. al. 2007; Tibben 2007: 169-170; Williams et. al. 2012, 2009). The disruptive force of HD is then obviously not limited to the sick individual alone, but it encloses the whole family. This aspect is illustrated by Thomas, who lives in a suburb to one of the major cities in the southern part of Sweden together with his wife Paula; she has been diagnosed with HD. At the time of the interview, it was not known whether their son, Jonathan, had inherited the gene (and thereby HD) or not. He has since then gone through genetic testing and learned that he is not a gene carrier for the disease. The adjustment forced upon Thomas and the family as a result of HD is experienced as a transition into an altogether different life trajectory, which started when Thomas noticed the first signs of HD in Paula. As her symptoms progressed, the disease also had a serious impact on their relationship as a married couple:

> Thomas: Well, we don't have a married life together any longer…no.

One of these lacking dimensions is the inability for Thomas to communicate with Paula due to the motor symptoms and cognitive symptoms that are part of HD (Hartelius et. al. 2009):

> Thomas: Yes…anyway, in a marriage, and that is important, you know. Then, communication is one of the most important things. I should have the possibility to communicate with my wife, and we haven't been able to do so in the same manner [since the onset of HD]. I haven't been able to get any feedback. And that has been a disadvantage for me, even when I had the company. I needed to have somebody…well, you sit at the kitchen-table and discuss. And I came home with a lot of problems, problems with alcohol at work or…eh… no money in the cash register or something like that, you know. I've been forced to take all decisions and I haven't had anybody to get feedback from. I couldn't go to our customers to get feed-back, I couldn't go to my employees to get feed-back.

HD also brought a number of significant changes for Thomas himself, who used to live a very active life as a self-employed entrepreneur, owning his own company with several employees. All this changed as Thomas started to notice the first signs of HD in Paula:

> Thomas: I sold my company in the year 2000, that's 10 years ago, when I saw that things were starting to be buggered up, and then I stayed at home for a number of years and helped Jonathan with his schoolwork, and things like that.

It seems almost inevitable that the issue of loss and the question of what 'could have been' if the disease had not struck become important and difficult issues for people to come to terms with. In the interview, both Paula and Thomas keep coming back to the disruption caused by HD:

> Paula: I think it's too early for me to get the disease. I could have been around 80 or something but 50…Jonathan hadn't moved out yet, hadn't left home when I got ill […] And I sort of thought that our lives should start, that me and Thomas should have a good time together as we got older.
>
> Thomas: This hasn't turned out as we expected, Paula? Buying a house in Thailand and…
>
> Paula: No…nothing…

In very much a similar way, Carla's life has to a large extent been centred on HD as a result of her husband Steven's diagnosis twenty years ago. At the time of Steven's diagnosis, they were both in their early to mid thirties and they had two children who now were at risk for developing HD. Both of their children went through genetic testing to find out whether they carried the HD-gene. Both tests came out negative, which means HD will not return to their family. At the time of the interview, Steven had, a few months earlier, passed away from HD. Carla looked back on a life with HD, and what could have been had the disease not struck their family:

> Carla: That's what you don't know? I remember one night a couple of years ago; I sat reading on the front porch because Steven had an assistant here. Those who lived across the street, they were the same age as us, and they sat there with a barbecue and a glass of wine. And I thought to myself: I wonder how that would have felt, really? Because those were things, I had never experienced, at that age in my life. We had the kids, and then it became…more to take care of…

As illustrated by Carla's and Thomas' recollections above, the lived experience of HD is laden with all those thoughts and emotions that arise when the disease disrupts your entire life and your family. Included within these thoughts and emotions are also feelings of responsibility which, according to Frank, guides people towards the moral commitments and responsibilities that illness calls them to (Frank 1995: 14-15).[4] As studies of individuals suffering from other serious diseases have illustrated (Harding & Higginson 2001: 643; Lewinter 2003: 368; Champlin 2009: 1533), there is a great tendency for family members to feel a strong sense of obligation towards an ailing loved one. Similar senses of responsi-

bility and obligation are echoed in our informants' words. Thomas, for example, states that despite all the changes that Paula's disease has brought to his family and marriage, he feels a deep and enduring obligation towards Paula:

> Thomas: The only thought I've been having is that all this should be for Paula's best, so she receives all the help that she can get.

Carolyn, whose husband is diagnosed with HD and who has three children who (at the time of writing) have not gone through predictive genetic testing for HD, points out the importance of being at hand if HD strikes yet another generation of her family:

> Carolyn: I hope that I'll stay healthy. That's what I think, because there's a lot that rests on my shoulders then. I'm thinking if my children become ill as well, I hope that I'll be able to be at hand there then.

A similar account is given by Emma who carries a difficult burden, not only in relation to her own family, with her husband who is diagnosed with HD and her two children who have tested positive for the disease, but also in respect to the sister of her husband who has also been diagnosed with HD. For this family, the impact of the disease will repeat itself in one form or another, as Emma's children eventually will become ill. Being the only individual in the family who will not be afflicted by HD, her life is structured in an almost total way by HD. Nevertheless, she feels the responsibility to carry on despite these harsh conditions:

> Emma: I'm there and I'm here, trying to stitch things together…a little bit there and a little bit here…so it isn't that strange that you sometimes feel like: Oh. I won't bother about all of this! But, then there is somebody who tells you that you can't do that. And that's really good, you know. That this inner voice tells you that you have to go on.

The important point to be made on the basis of the material presented above is the holistic nature of the illness story. Communicative action then organizes the experience and the meaning of caregiving in terms of this totality, as part of a much wider story that incorporates feelings of loss, love and moral responsibility towards the sick individual. The meaning of caregiving can then not be separated from all the other aspects that are part of the illness story.

This holistic nature of the communicative action is what constitutes the basis for the requests made by the affected families towards the system. Jimmy, who has a HD- affected mother to whom he acts as a primary caregiver, went through genetic testing that showed that he is not a gene carrier for HD. However, being out of danger himself, and relieved by the fact that he will not become ill, he now faces the difficult and emotional task of caring for his mother. A situation in which, and to Jimmy's sorrow, the roles between mother and son are reversed:

> Jimmy: All I want to do is just to be with her, I want somebody else to take care of all that's related to the disease, like the National Insurance Agency or the municipality. I wish somebody else would come and take care of all that so I could come around and only be her son. I would like to just come around, to sit down and have a

> chat. But there is always something that has to be cared for […] I can never go over and just have a chat.

To receive assistance is thus a chance for Jimmy, not only to receive help with the concrete care of his mother, but also, once again – and before it is too late – to enter a relationship with his mother in which he has the chance to be her son and not only her caregiver. This is also an important part of the dilemma that Thomas faces when he asks the welfare system for help in the form of a personal assistant to help care for Paula. The holistic nature of this request is clearly reflected in how Thomas, who, as the primary attendant of Paula, feels the need to be available to her all the time. A personal assistant would allow Thomas to take more time off from an often difficult situation at home, giving him the opportunity to do something as simple as picking mushrooms in the local woods, which he views as his way of 'recharging his batteries'. Caregivers often use strategies like these as a way of dealing with the difficult situation that they face (Shyu 2000). The possibility of a personal assistant, as he has requested, would provide him with a greater opportunity to take time off without being worried about Paula:

> Thomas: It's not so fun if I know that Paula is home alone, and if I'd go off I would have a hard time relaxing. I admit that, but there is no problem if there is someone with Paula. That's why I believe a lot in this idea of getting personal assistance for her. Then she'll be working every second weekend and I can go to the woods to pick mushrooms, you know.

As shown by the empirical material, the meaning of the requests made to the welfare system is encapsulated within an illness story that takes its point of departure in the life trajectory of the whole family. However, as we will show below, the welfare system applies an instrumental discourse that is grounded in legal terms rather than a holistic illness story.

The Meeting between the Families and the Welfare System

In their contacts with the welfare system, the affected families are confronted with an objectifying and technocratic legal discourse employed with a strategic meaning to achieve *goals that are motivated from the perspective of society as a whole*. This legal discourse substantiates the voice of the welfare system that defines the rights of the families and the measures that are provided by the welfare system.[5] The legal act that covers the right for personal assistance exemplifies this instrumental and technical discourse that confronts the families as they seek help from the welfare state. The first section in the Act provides the legal definition of those who are entitled to personal assistance:

> ***Section* 1**
>
> This Act contains provisions relating to measures for special support and special service for those

1. who are mentally retarded, are autistic or have a condition resembling autism,

2. who have a considerable and permanent, intellectual functional impairment after brain damage when an adult, the impairment being caused by external force or a physical illness or,

3. who have some other lasting physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are major and cause considerable difficulties in daily life and, consequently, an extensive need for support or service (SFS 1993:387).

And section seven and nine contains a specification that defines the content of the assistance offered:

***Section* 7**

Persons who are referred to in Section 1 are entitled to measures in the form of special support and special service pursuant to Section 9, subsections 1-9, if they need such assistance in their daily lives and if their needs are not satisfied in some other way. Persons who are referred to in Section 1, subsections 1 and 2, are also entitled, if the prerequisites are the same, to measures pursuant to Section 9, subsection 10 (SFS 1993:387).

***Section* 9a**

Personal assistance pursuant to Section 9, subsection 2 refers to personally designed support that is provided by a limited number of persons for anyone who owing to major and lasting functional impairments needs assistance with her or his personal hygiene, meals, dressing and undressing, communicating with others or other help that requires extensive knowledge about the person with a functional impairment (basic needs) (SFS 1993:387).

Carla is very much aware of the importance of this legal discourse, and the necessity of transforming hers and Steven's illness story into this discourse in order to communicate with the welfare system. This awareness is also driven by the fact that she and Steven can not get by on their own any longer, the progression of the disease has come to the point that they both see no other alternative than to seek help from the system. This is a situation in which they are very much dependent on the assessment made by the system:

> Carla: You end up in a position of dependence because you can't get by without this help that I really don't want. I would like to take care of my family by myself, but in the end, you feel that you really need the help. Then, you end up in a position of dependence […]. You're dependent of the assistance, dependent of society.

There is a feeling of being powerless when Jimmy voices his frustration towards the assessment made by the welfare system when they applied for assistance. As a

way to evaluate their request, a welfare administrator from the Social Insurance Agency made a home visit in order to get a clear picture of their situation:

> Jimmy: […] It's a great frustration with the Social Insurance Agency. It…they're sitting on all the power and all you get is a letter in which there is... like a stamp that says: No! And that's when they've been around to look for themselves, they've been here with my mother for one hour, just sitting around a table, like we do, and talking. That's all they've seen. They don't want to see her doing anything, *to see how it is* [my emphasis] Around a kitchen table. Why can't they accompany me in every moment [of the caregiving] instead? So they can really see. If that were the case, I could accept a refusal [on our application].

A similar response comes from Carla in conjunction with the welfare administrators' visit to their home to evaluate their situation:

> Carla: It's just this with being trusted…many times I've said to Steven: Don't pull yourself together just because they're here! Because they're here to see just how it really is. And don't say that everything is Ok […] I've tried to get, and also got, consultations on my own with the Social Insurance Agency and the municipality, so that I don't need to offend Steven in front of them. Because it can feel like an insult when you're saying: He's doing this, and he's doing that.

Jimmy's and Carla's frustration can then be interpreted as a reaction against a misrepresentation of their illness story. Their perception of *how it is* in their everyday life disappears as the legal discourse decontextualizes and simplifies the holistic aspect of the illness story in order to mark out just those aspects that can be arranged in accordance with the overall goal or objective of the system (Feenberg 2010: 157-180). The anger directed by Elizabeth towards the welfare administrator who suggested a divorce illustrates the strain and the tensions that arise in the wake of this simplification made by the system. However, from the perspective of the administrator, who views Elizabeth's situation in the light of the framework of law and of the system, a divorce is of course one rational solution that would legally force the welfare system to take responsibility for Brian. The difference in perspectives is also part of Thomas' account:

> Thomas: But the National Social Insurance Agency is giving us a hard time, of course. She doesn't need any help. Even though she sometimes chokes on her food, and is unable to take a shower, or rather, doesn't want to take a shower. So, she needs help all the time.

In relation to the lifeworld and communicative action, the use of a legal discourse constitutes the most rational way for society to deliver all those entitlements that are grounded in the rights that every individual can make a claim to as a citizen. This reduction can then be seen as a necessary step towards achieving the kind of transparent and effective large-scale redistribution of resources necessary of the welfare system in order for it to function in accordance with its overall goal. Zygmunt Bauman discusses modernity in terms of a 'quest for order' (Bauman 1991). Modernity, according to Bauman, is a fight of determination against ambiguity, of semantic precision against ambivalence, and fuzziness (Bauman 1991: 7). The entitlements provided by the welfare state can be seen in light of this very

modern 'quest for order', providing both social and political security in the form of legal rights as a safe-guard against an economic system that works according to the logics of free-market capitalism. However, this quest for social and political order comes with a price in the form of feelings of alienation towards society-at-large. These feelings of alienation on behalf of the families exemplify a dislocation in relation to how alienation is experienced within the welfare state and modern society. As alienation is experienced in conjunction with labour and processes of commodification, it 'recedes further and further into the background as the welfare state becomes established' and accordingly can be considered in terms of 'induced deformations of the lifeworld' (Habermas 1987: 349, 384). This is illustrated by Thomas' bitterness, not only towards the welfare system, but also towards society in general:

> Thomas: They haven't even looked up what kind of disease she suffers from, even though there are only about 600-700 people in Sweden who…They haven't even…they just used a stamp: No! No, doctor's certificate, they didn't even wait for that […] Yes, I feel bitterness towards them. Over what society can't do…that they can arrange everything else, but not when somebody becomes seriously ill.

However, these feelings of frustration and alienation are not the only reactions displayed by the families; these feelings are also a source of empowerment. This is something we shall investigate in what follows as we endeavour to break down the dichotomy between lifeworld and system. Instead, we shall open a 'Third space' within which the opportunity for empowerment presents itself.

Hybridization, 'Third Space' and Empowerment

The previous section points towards a tension-laden confrontation between the affected families and the welfare system, as the lifeworlds of the former meet the instrumental rationality of the latter. For Habermas, as well as for Frank, this tension-laden confrontation between lifeworld and system represents the dark side of modernity, which both Habermas and Frank represent in terms of a form of colonization upon the lifeworld on behalf of the system (Habermas 1987: 332-373, Frank 1995: 146). The Swedish state is, to be sure, a formidable opponent to run up against. And while the logics of the welfare system may seem highly rigid and insurmountable, some of the people we have spoken with have found ways of proceeding, to meet their own goals. Carla describes the difficulties, but also the importance, of expressing oneself in the legal discourse used by the system when trying to formulate an appeal against a decision made by the welfare system, in this case the local municipality:

> Carla: If I had written those papers, I might have written them in about the same way as he [the attorney who helped her to compile the appeal] did, but I would have written them on the basis of my feelings as a close relative. He translated those feelings to a juridical language…and then it becomes this [Carla shows an appeal that she

> and the lawyer were compiling in response to a rejection by the local municipality]. He was able to transmit our feelings with different words.

Carla's experience, as described in the citation above, was one that recognized that the language of the welfare system operated along a different register than the emotional reality of her everyday life. She employed an attorney to help her communicate the experiences of her lifeworld in the formal and instrumental language of the system. The result was a hybrid of sorts, which mixed the emotionally laden information she wished to communicate with the instrumental language comprehensible to the state. As Mikhail Bakhtin points out, hybridity is 'a mixture of two social languages […] separated from one another by an epoch, by *social differentiation* or by some other factor' (Bakthin 1981:358; quote taken from Young 1995: 20, our emphasis). Caregiving in this case, must be understood as more than a medical practice, or more than a politically steered administrative function of the state. Regarding the argument in this way, we find that between the lifeworld of families affected by HD and the rationality of the system, there is a mixture of communicative and instrumental action that has the potential to lead to new hybrid modes of communication. Furthermore, as Homi Bhabha points out from a post-colonial perspective, 'forms of popular rebellion and mobilization are often most subversive and transgressive when they are created through *oppositional cultural practices*' (Bhabha 1994: 20, our emphasis). In the case of caregiving, these oppositional practices come forward, not only in the form of documents drafted by attorneys, but also in the form of patient organizations and support groups. These patient organizations and support groups work in a manner not entirely dissimilar to the practices of Carla's attorney, engaging in activities that open up what Bhabha terms as a 'Third Space' (Bhabha 1994: 36-39). This is a space of communication and action that is not based on the illness stories of the affected families, nor on the legal discourse employed by the system, but on a combination or amalgamation (Lundin & Åkesson 1999: 7-15) of both.

In the Southern part of Sweden, a local support group for family members exists as part of the national patient organization for people who are neurologically disabled. Within this support group, the participants come together regularly to discuss the various problems that they face as families affected by HD. The foundation for the collective strength offered by the support group resides in the mutuality and sharing of the same lifeworld. In this way, the support group reproduces the meanings within the illness stories through communicative action. Jimmy reports about the way the support group has helped him in his situation:

> Jimmy: We're all in the same situation. We come to hear what kind of problems the others have had; what they have succeeded with and what they have not succeeded with. If there's a problem, you can discuss it because there's bound to be someone else who has faced the same kind of problem; somebody who can help me get around that problem.

Emma is also a member of the same support group, and for her the group has become the only place where she has been able to raise the different kinds of difficulties that she faces in her everyday situation:

> Emma: Yes, it [the support group] has meant a lot. Mainly because it was sort of the only place you could turn to. And say, like: Oh, now he's doing this and this! [referring to her husband who is diagnosed with HD]. But, that's normal, said somebody who has been through the same kind of problem. So, because of this it has meant a lot to have the support group.

The support group provides a sort of 'breathing space' for the participants where they can meet and freely ventilate various aspects of the disease. This is something that has been observed in other contexts than HD, for example among individuals affected by burnout syndrome (Hammarlin 2008). Moreover, the support group gives the participants a chance to defend their illness stories and the meaning contained within these stories against the legal discourse endorsed by the system. It becomes their way to regain their own voices and their own meanings in relation to the definitions made by the welfare system.

Another crucial and important aspect of the establishment of this 'Third space' is facilitated by the national patient organization for people who are neurologically disabled, which offers in-depth knowledge of social welfare laws. Carla, who is active in the same local support group as Jimmy, indicates that these courses provide both strength and knowledge to the participants who take part in them. Important here is the degree to which it helps to define the extent of their legal rights in relation to the various parts of the welfare system:

> Carla: We've got this strength through the courses at Valjeviken [the location on which the courses are held]. There we get to know what I have the right to claim, and what I don't have right to claim. We've been taught to never accept a decision by mouth. If the administrator says that it is no use trying to apply for some entitlement because you will not get the approval…Ok, no. I will have that in writing please, because that means you've just been given a decision in this matter.

The local support group plays an important role in opening a new space for potential action in which the families make use of both their illness stories and the legal discourse as a means of empowering themselves and reacting against the dependency they feel towards the system. Moreover, their response also reflects the organization of society and, in extension, the intrinsic aspect of modernity, which has given rise to those divisions that are the key-concepts within this article: lifeworld and system, communicative action and instrumental action. Consequently, as Habermas acknowledges, the 'language of law, unlike the moral communication restricted to the lifeworld, can function as a transformer in the society-wide communication circulating between system and lifeworld' (Habermas 1996: 81). Moreover, these new forms of empowerment, coming across through a 'Third space', break the dichotomy between the lifeworld and system, as patients, their families and patient groups work in hybrid manners to facilitate change, and meet the rigidity and dominant position of the Swedish welfare system. Modernity does

have its dark sides, which can be diagnosed as a colonization of the lifeworld, social pathologies and crises (Baxter 2011: 168); but, as we have shown in this section, those intrinsic aspects of modernity that give rise to these diagnoses also carry the potential for the establishment of a 'Third space' through hybridity. Here, Robert Young notes that the double logic that is encapsulated within this hybrid 'Third space' of communication and action 'could be said to be as characteristic of the twentieth century as oppositional dialectical thinking was of the nineteenth' (Young 1995: 27). Because of this hybridity, the act of regaining your voice in the twentieth century, which Arthur Frank depicts as a form of 'post-colonial construction of the self' (Frank 1995: 10), also contains the possibility to undermine the instrumental action of the system by attaining the language and practices employed by the opponent.

In this article, we have performed a cultural analysis of the meeting between families involved in caregiving in cases of Huntington's disease and the welfare system. Other studies performed upon the interaction between families affected by HD and healthcare services within the United Kingdom and USA have shown that caregiving families were concerned by such issues as access and affordability to health care services, as well as a lack of knowledge about HD on behalf of health and welfare services. In order to meet these challenges, Skirton et al. requests an alignment between the needs of the affected families and the services provided by the welfare system (Skirton et al. 2010: 508). This cultural analysis has however shown that the interaction between the affected families and the welfare system is concentrated around differences in communicative action and an instrumental legal discourse. Compared with other studies, performed for example within the medical sciences, this study exemplifies how intrinsic features of modernity form a crucial part in the shaping of how families involved in family caregiving experience the interaction with the welfare system. The importance of these intrinsic features of modernity implies that an alignment between the needs of the affected families and the welfare system must also encompass an alignment between communicative and instrumental action, as well as the dominance attained by the welfare system. However, our analysis has also shown how families involved in caregiving are able to overcome and undermine the dominance attained by the system. This occurs through a 'Third space' that we have characterised as a hybrid form of action, as an amalgamation of communicative and instrumental action. The last part of the article has exemplified this aspect in the context of a local patient support group, whose activities constitute a movement between their own illness stories and the legal discourse used by the system. In this context, an empowering 'Third space' gives them the opportunity to act, in a more instrumental manner, towards the system. We link the emergence of this hybrid with the cultural and social process of modernization and the separation between lifeworld and system. This shows how new forms of empowerment arise from these intrinsic aspects of modernity. Our investigation therefore points towards how the divi-

sion between communicative and instrumental action constitutes, not an end-point in regard to cultural processes within the late modern society, but rather a point of departure from which hybrid forms of communications and action arise. As such, these hybrid forms represent an important cultural phenomenon to consider in our attempts to understand cultural and social change within modernity.

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Notes

[1] Huntington's disease (HD) is caused by a mutation in the HD gene and the pattern of inheritance is autosomal dominant, which means that a child of an affected parent has a 50 % risk of inheriting the mutated gene (Huntington's Disease Collaborative Research Group, 1993). The mutation is fully penetrant, indicating that its presence always leads to disease. The disease is characterised by a combination of neurological, psychiatric and cognitive symptoms. In general, the onset of the neurological symptoms appear between 35 to 45 years of age, and the progression of the disease always leads to death within 15-20 years after the onset of the neurological symptoms (Ross & Tabrizi 2011). No disease-modifying treatment or cure is available. The formal clinical diagnosis is based on the presence of unequivocal signs of motor dysfunction (Huntington's disease Study group 1996). These neurological symptoms include disturbances of mainly involuntary movements, where the control of voluntary movements becomes more and more difficult as the disease progresses and finally being impossible to coordinate for the affected individual. The psychiatric symptoms of HD, which most often are present before the onset of the neurological symptoms, include personality changes, irritability and aggressive behaviour, as well as depression (Johnson et al. 2007; Julien et al. 2007). HD also includes cognitive disturbances involving deficits in attention that progress to dementia in the later stages of the disease (Stout et al. 2011).

[2] In Sweden, social insurance is individually based and compensates loss of income when a person is unable to support him/herself by working as a result of, for example, an illness or caring for a child at home. Social insurance is administered by the Swedish Social Insurance Agency, which is mainly financed through taxes. Social insurance includes universal benefits and means-tested benefits as well as income-related benefits. In the Swedish health-care system, responsibility for health and medical care is shared by the central government, county councils and municipalities. The role of the central government is to establish principles and guidelines for care and to set the political agenda for health and medical care. Responsibility for providing health care is decentralized to the county councils and, in some cases, municipal governments. Sweden's municipalities are responsible for care for elderly people in the home or in special accommodation. Their remit also includes care for people with physical disabilities or psychological disorders.

[3] The integration of modern societies is not only, as discussed by Brännström (2009: 244) and others (Baxter 1987; Scambler 2001), achieved through language, culture and communicative action, but also through money and administrative power. This process of societal differentiation came to be established in subsequent waves, where the Western democratic welfare state constitutes the latest formation in this evolution towards a greater societal differentiation and complexity. The establishment of social welfare policies is meant to counteract those extreme disadvantages and insecurities that come with the functionality of the capitalist economic system. However, the establishment of various welfare policies, notwithstanding their capacity to provide social security, is not without negative effects, since these policies locate more and more decision power in the hands of experts and administrative structures whose decisions are removed from contexts of the lifeworld of those clients who interacts with these welfare systems (Buechler 1995: 445).

[4] The source of this commitment and responsibility is traced by Arthur Frank, on the basis of the philosopher Emmanuel Levinas, to reside in the communicative body and the obligations imposed by the human face (Frank 1995: 14-15, 157). The human face opens, in Levinas highly tensed language, "the primordial discourse whose first word is obligation" (Levinas 1969: 201; Clifton-Soderstrom 2003). The emotions and feelings conveyed by the human face impose a feeling of responsibility through the face-to-face encounter with another human being, and these face-to-face encounters harbour an inherent ethical obligation towards another

human being, compelling an individual to be there for the individual in need of care and compassion (Lavoie et. al. 2006: 228).

5 According to Deflem (1996), the emergence of this legal discourse can be ascribed to modernity and the separation between lifeworld and system, a condition in which morality has become a personal and subjective matter of concern, whereas law has more and more attained the form of a functional and technical tool for erasing ambivalence and achieving transparency on behalf of the system (Deflem 1996: 6-7).

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