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## Cells in Culture, Cells in Suspense

### Practices of Cultural Production in Foetal Cell Research

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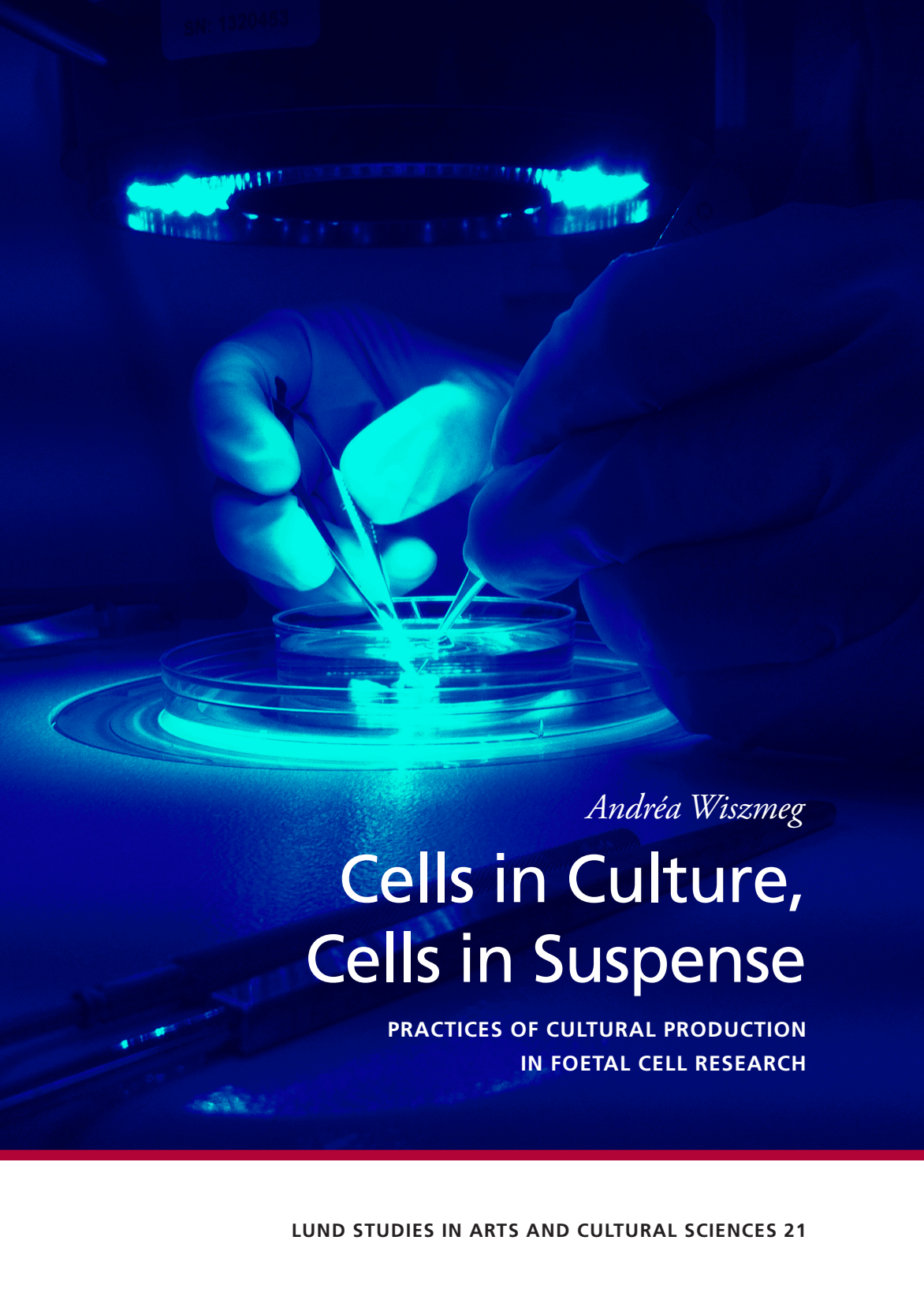
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*Andréa Wiszmeg*

# Cells in Culture, Cells in Suspense

PRACTICES OF CULTURAL PRODUCTION  
IN FOETAL CELL RESEARCH

CELLS IN CULTURE, CELLS IN SUSPENSE



# Cells in Culture, Cells in Suspense

Practices of Cultural Production in Foetal Cell Research

ANDRÉA WISZMEG



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Malmö, November 5, 2018

## Introduction

### The phenomenon of foetal cell suspension

In a petri dish, under a microscope in sharp, focused light, lies a small, aborted human embryo. The room is otherwise in darkness. This and other human embryos are the raw material for the development of a cell therapy, in a medical trial with transplantations to patients with Parkinson's disease. The embryo is a central object in the trial, as well as being central to this thesis. As it interacts with individuals from different communities governed by different norms, rules and priorities, it transforms from its original shape. It has been aborted and donated to research, then harvested by a nurse at the abortion clinic. It now waits to be disassembled, and the relevant parts of its brain plucked out and disassociated into a solution, a cell suspension – by neurobiologists. The rest of the embryo will be disposed of, after a number of tests for contagion have been performed. Its final fate is the cellular and neural integration into another living person or a rat, in the form of a therapeutic or experimental transplant.

This embryo is the starting point for the cell laboratory, when creating the solution of cells that is to be used for producing the cell transplants. These processes push the boundaries for what can be done with human embryos in the laboratories of regenerative medicine. And, as regenerative medicine pushes the technical horizon of what is possible, relations of life and death are reordered too. The transformation of the embryos from fleshy and gory biological waste, into potentiality in the shape of cell suspension, turns them into objects of hope and promise for the patients. The inherent vitality in these cellular units makes foetal cell transplantation a phenomenon interesting to investigate, by following its vitality through

different circuits and economies of knowledge, meaning, value and material transformations, on its trajectory to be transferred into a new individual, living organism.

The cells derived from foetal material and studied in this thesis originate from early-aborted embryos, within the age span from six to nine weeks' gestation<sup>1</sup>. The cell suspension produced from them will be used in a transplantation trial with people afflicted with Parkinson's disease. The disease is a severe but quite common neurological affliction, with approximately 20,000 people in Sweden living with the disease.<sup>2</sup> A patient can display a number of different mental as well as cognitive and physical symptoms, the best-known of them probably being stiffness and tremors. The reason for the development of the symptoms is considered to be a reduced or malfunctioning production of dopamine, which is a neurotransmitter that regulates our mood as well as the communication of movement between the brain and the rest of the body. The goal of the transplantations is for these cells to embed in the brain of the patient and for them to start aiding the lacking dopamine production. As described

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<sup>1</sup> The term *foetal* will be employed throughout this introduction when referring to the procured tissue and the cells, as well as to the processed cell suspension itself. The term *embryo* will however be used when referring to the donated abortion material as a whole, as it best describes the developmental stage of the donations. Even though the TransEuro trial mainly uses tissue from donations developmentally defined as embryos, their website defines the cells used as foetal. Therefore, I choose to adopt that terminology when talking of the processed tissue, the cells or the resulting suspension. This choice of term also minimizes possible confusion with human embryonic stem cells (hESC). The term embryo refers to the period of development when organs are being formed. In the human, it is defined as up to 7 weeks + 6 days post conception (pc). The foetal period starts from 8 weeks + 0 days pc. It should be noted that the trial occasionally procures and processes cells from what are by definition early on aborted foetuses, up until 10 weeks pc. This is because measurements and calibrations sometimes are uncertain concerning the exact gestational age pc. Therefore all donations within a period of 5–9 weeks pc may be used in the trial. The tissue may therefore sometimes by definition be derived from tissue within the foetal developmental stage. Up until this point in development, the embryo does not have all the bodily organs formed, nor functioning. There is not yet a developed circulation system and the cells survive in part independent of microcirculation.

<sup>2</sup> Sources: Parkinsonförbundet (Swedish Parkinson Association): <http://www.parkinsonforbundet.se/meny2/Om%20Parkinsons%20sjukdom/Vad%20%20E4r%20Parkinson.html>. (Links retrieved: October 2, 2018)



earlier and as will be described in more detail later, it has to go through some changes to reach there.

But before getting to the patient, the cells need to be transformed on many different levels. They take their departure from the aborted embryo, and move on to the laboratories and into cell suspensions ultimately to be transplanted into the brains of research animals, and later on to be part of clinical trials and transplanted to the brains of patients. Along the way, shapes change, and plenty of new acquaintances are made. As the cell suspension materializes, it makes relations with staff, machines and tools of the abortion clinic and laboratories, as well as with the research objectives of the trial and the documents guiding the procedures. The expectations of researchers and patients entangle with the material processes, and aid the transformation. In one sense, the conceptual foetal cell suspension becomes not one, but many (Mol, 2002). Along with its manufacturing, other entities and objects – as well as emotions, concepts and knowledge – are produced or potentialized. So what are the cultural phenomena that are produced along with the object of the foetal cell suspension? How are these phenomena connected to the processes in the laboratories, as well as to experiences of Parkinson's patients and relatives?

## The emergence of a field

As the embryos are materially transformed in the laboratories, so are their interfaces with communities and contexts. Previously having relations with a broad range of people with different relations but a somewhat common conceptualization of them; they are turned into an anonymous solution with therapeutic properties which not at all as many have either insight into or information about. The affinities with human origin as well as contact with the broader society are cut off. The aborted embryo is transformed into what will here be defined as a *bio-object* (Vermeulen et al., 2012; Holmberg & Ideland 2011). This concept describes a biological artefact that challenges our notions of categories such as nature and culture, living and dead, made and found. It is in a constant flux of meaning and knowledge with science and society and it transitions between states and mediates between categories. It can be said to be liminal. By being an

object with regenerative properties, it is given agency to locally rearrange cultural, conceptual as well as material borders – of life and death and of what is considered whole and part. Although acting in relative anonymity in broader society, it has the power to set biological, technical as well as cultural processes in motion. As the numbers of bio-objects grow with developments in medical technology, so do the possible areas in medicine and health care being challenged ethically in contact with these biological artefacts.<sup>3</sup> Looking into the history of cell transplantation, we can see that there is a long history of producing bio-objects.

Transplantations of grafted brain tissue in animals are not new and were done already as early as in the late 1800s, with proof of cell survival. Grafting means that a tissue piece is transplanted into the afflicted brain, in which it is meant to integrate. Growth in transplanted brain tissue was shown in 1909. In 1979 the first tissue grafting that was also proven functionally successful in the new host brain was carried out in an animal model of Parkinson's disease (Boronat-García et al., 2017). Since then, many different approaches and techniques using different tissues have been attempted, with varying success. Even if proof of principle has been shown over and over that the transplants do integrate, innervate and produce dopamine, the results in individuals have shown high variability. The tissues or cells used and refined throughout the history of cell transplantation in the brain have varied. What they have in common is that they all to

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<sup>3</sup> New boundary-transgressing medico-technical inventions challenge researchers, as well as care professionals, on a daily basis. Access as well as cost-efficiency have to be calculated when choosing between different medical needs. Many biomedical innovations also mix animal and human tissues, or biological and mechanical components, creating unforeseen ethical issues. In Ethics or in Moral Philosophy as disciplines, there is a long tradition of seeking to establish and analyse different principles of moral or ethical action. Roughly defined, the principles can be divided into philosophies of obligation and of consequence. However, in trying to handle the unpredictable dilemmas that new technologies may pose, these philosophies can never be more than guiding. As a cultural analyst and ethnologist, my interest lies primarily in “what is *considered* the right choice”, over “what *is* the right choice” (Hermerén, 1996; Hansson, 2006), and how these considerations are carried out in real-life situations in the laboratories of the researchers, faced with dilemmas posed by producing the bio-object of foetal cell suspension. This may be called a kind of ‘ethics-in-practice’ (Hansson, 2006; Lundin, 2012; Nordgren & Hansson, 2019) or ‘everyday ethics’ (Fioretos, Hansson & Nilsson, 2013).

varying extents are objects that have produced or transgressed different boundaries within or between the different disciplines or professions handling them. They have all also to varying degrees acted as border-crossing phenomena of knowledge, materiality and of life; as bio-objects (Vermeulen et al., 2012). Some may have challenged upheld boundaries between species<sup>4</sup> or individuals; some may have required new legislation following the technical innovation. All of them have had the common aim of prolonging or enhancing life in one organism, conditioned by death or interruption of another.

Human foetal ventral midbrain (VM) neural cells – like the ones harvested from embryos as described in the introduction – are still one of the most promising cell sources, partly because they are relatively reliable in not growing tumours. Ethical concerns originating from the embryo being aborted,<sup>5</sup> as well as scarcity of tissue, however, make them impossible as a long-term and large-scale solution in transplantation medicine. During the 1980s, research was also conducted using a kind of neuroendocrine cell<sup>6</sup> in transplants, which was later shown to be to unreliable and not effective enough for further research. Still, these were the first kind of cells to be tested in a clinical trial with Parkinson's patients. In the late 1980s and onwards, transplantation of VM cells was tried and evaluated in a number of clinical trials (Lindvall et al., 1989; 1990), researchers at Lund University being pioneers in the field. The results varied greatly, however, although some individuals showed clear improvements. The study design used in these trials, was eventually criticized for its lack of control groups and inability to discard a placebo effect. In 2001, a double-blind trial with these cells was conducted, in which a control group receiving so-called sham

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4 E.g. by xenotransplantations between species

5 Such as using embryonic cells in themselves as they have a potential to life, as well as the issue of who has the right to give consent on behalf of the embryo. In Swedish legislation, it is the right of the aborting woman to do so (Transplantation Act 1995:831; [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm\\_sfs-1995-831](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm_sfs-1995-831), and the bylaw SOSSF 2009:30; <http://www.socialstyrelsen.se/sosfs/2009-30>. Links retrieved November 27, 2018).

6 Cells that receive neurotransmitter signals and as a response release hormones into the bloodstream.

surgery, was included (Barker et al., 2015; Boronat-García et al., 2017).<sup>7</sup> These double-blind studies including ‘sham surgeries’ did, on other hand, incur criticism for being unethical concerning the risk-benefit balance of the participants in the control groups (Macklin, 1999; Idvall, 2017). The double-blind studies with similar designs showed rather modest and varying results, with no clear benefits for the transplanted group. Instead, many cases of dyskinesia – involuntary movements – were discovered among the recipients of the foetal material. As this is considered an unacceptable side effect due to its irreversibility and negative effect on quality of life, this could have meant that cell transplantation therapy on Parkinson’s disease would have needed to find a new research line.

But a new flame of hope was lit with the discovery and development of human embryonic stem cells (hESC) in the early 2000s (Ideland, 2002; Persson and Welin, 2008).<sup>8</sup> As of today, hESC has shown to have the same or better efficacy concerning dopamine release and innervation in animal models (Kikuchi et al., 2017). The obstacle in using hESC for transplants in medical trials has so far been the greater risks of developing tumours, associated with these cells. However, a transplantation trial involving hESC was conducted during 2017, and four patients were transplanted with these cells in California, USA. The early data on clinical safety look promising according to the researchers.<sup>9</sup> Another avenue explored in cell transplantation research is human-induced pluripotent stem cells (iPSCs). The technique to utilize them was invented in 2006 in Japan. As they are

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<sup>7</sup> This means that the control group of the trial undergoes surgery, but no transplantation is actually performed. Another version is that the control group receives a different but therapeutically equivalent transplant by the same procedure. However, this was not the case in 2001.

<sup>8</sup> These cells have to a greater extent been conceptualized as boundary objects as well as bio-objects by earlier social and humanist research. This may be because, as boundary objects, they are of common interest to a broader range of scientific disciplines as well as to a larger variety of medical applications. As they depend on a more obvious degree of technical manipulation, and enable immortal cell lines, they also more obviously challenge the boundaries of life and death and of what is considered natural and manufactured.

<sup>9</sup> Sources: <https://parkinsonsnewstoday.com/2017/04/26/first-dose-group-parkinsons-stem-cell-trial-successfully-transplanted/>, <https://globenewswire.com/news-release/2017/04/25/970944/0/en/International-Stem-Cell-Corporation-Completes-First-Cohort-In-Parkinson-s-Disease-Clinical-Trial.html> (Links retrieved May 12, 2018)

derived from adult cells and reversed into stem cells, they may be harvested directly from the body of the patient to be transplanted. This diminishes a lot of ethical debate and concerns about using embryonic materials, which up until now has been the only source of stem or progenitor<sup>10</sup> cells. Such source of cells would of course be invaluable to cell transplantation research and practice. However, as was the case with hESC, tumour growth is still a problem in animal models with iPSCs, as well as a reported low efficiency in cell reversal. Still, a recent study has shown that cells transplanted in primates with Parkinsonian symptoms survived and produced dopamine. The animals also displayed reduced symptoms in the form of increased spontaneous movement (as opposed to the previously experienced rigidity), after the transplantation (Kikuchi et al., 2017). Nevertheless, there are many obstacles ahead on the road towards a cell transplantation field free of foetal and embryonic tissues and the ethical and practical concerns that come with them. The foetal tissue and the cell type itself have already shown to be clinically safe, as well as to be able to produce good results (Piccini et al., 1999; 2000). The challenge now is to successfully transfer the methods and the template used with foetal cells to future large-scale multi-site trials, using other more sustainable cell sources. In relation to the fast developments and future medical applications of these technologies, it is crucial to analyse and understand how the bio-object is technically produced in the field of cell transplantation research, but also is a production of social and cultural context.

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<sup>10</sup> A progenitor cell is a cell that has the potential to differentiate into a specific cell type, and is programmed to develop in that particular way.

## INTRODUCTION

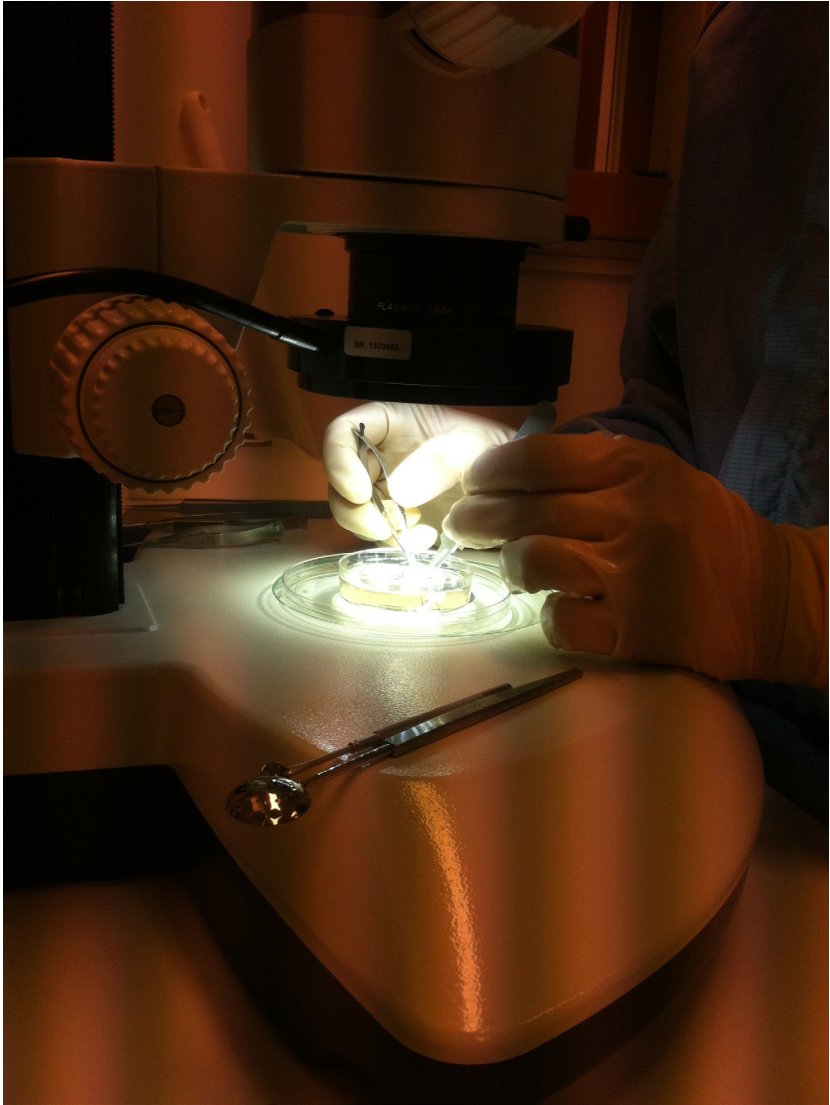


Figure 1: Making cell suspension, making a bio-object.

## Aim and research questions

The aim of the thesis is to culture analytically investigate the transformations of embryos and foetal tissue into foetal cell suspension. Proceeding from the background given on developments in the cell transplantation field, the focus is specifically on how meaning and knowledge produced in this process, makes the foetal cell suspension a bio-object.

The introductory chapters function as a backdrop, accounting for the conditions and contexts in which the cell suspension and its cultural ‘by-products’ or phenomena are manufactured<sup>11</sup> or related to. Their purpose is to explore and explain the culturally *produced* as well as culturally *productive* properties of foetal material and of cell suspension. They examine the interactive roles of these phenomena *between* different contexts and processes using primarily the concept of bio-objects.

Investigating the of refinement of foetal material into cell suspension can offer a better understanding of the culturally ambiguous embryo and its role in regenerative medicine, as well as of the strategies being developed by the researchers working with it to handle and avoid cultural and ethical uncertainties. The chapters and articles address and

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<sup>11</sup> Donated cells cannot in themselves be products. To use the term *manufacture* in describing and analysing the processing of donated foetal tissue into cell suspension is therefore by medico-technical definitions incorrect. Since no major alteration or manipulation of the material or its characteristics or properties is made ([https://lakemedelsverket.se/upload/lvfs/LVFS\\_2008-12.pdf](https://lakemedelsverket.se/upload/lvfs/LVFS_2008-12.pdf)), it therefore cannot be called a product per se. Instead, the tissue procurement and use is regulated under the Swedish Transplantation Act, and the tissue considered is a donation ([https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm\\_sfs-1995-831](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm_sfs-1995-831), §11, 12, 13). However, to analytically view the cell suspension as a *manufactured product* is, I argue, in line with how manufacturing is generally and broadly defined and understood as “the act or process of producing something” (<https://www.merriam-webster.com/dictionary/manufacture>). It is thus legitimate to call it a product in the sense of it being brought into existence by physical and/or intellectual effort (<https://www.merriam-webster.com/dictionary/produced>). The cell suspension could arguably not exist as a transplant without the labour of the aborting and donating women, or the midwives at the abortion clinic and the researchers involved in the laboratories of the trial. In that very basic sense, the foetal cell suspension is a product and will be addressed as such in this thesis. (Links in this note retrieved on November 18, 2018)

problematize specific products or processes found when researching the making of the foetal cell suspension. They look into what is set in motion and enacted in different contexts, by the refinement from foetal tissue to cell suspension. Besides being a cell source of therapeutic value and an object of intense study for the natural and medical sciences, foetal material makes an interesting object of study for the social and cultural sciences as well.<sup>12</sup> As it sets in motion negotiations of social, material and cultural relations and of ethical issues – in the laboratory as well as outside – it is an object suitable for such an ethnographic investigation. Its ability to make visible, as well as to push social, cultural as well as biological boundaries, offers many possibilities for ethnology to address issues of the same character.

As the roles and rationales of the embryo, and of the foetal material and the cell suspension – as well as that of researchers, patients and of lay-people – operate on different levels and in materially and socio-culturally somewhat different arenas, four research questions were formulated in order to be able to reach different kinds cultural products in each article or chapter. This means that the research questions are specific for the chapters and articles included, while the overarching aims of the thesis are targeted and discussed more broadly in these introductory chapters. One research question was addressed and discussed by each article or chapter, as follows:

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<sup>12</sup> The existence of cells was discovered already after the invention of the microscope during the seventeenth century. However, they were somewhat unthinkable as common objects in themselves until the nineteenth century, when the cell theory – the idea that all living things are made up of cells – was established (Uddenberg, 2015) Different kinds of cells are of course perfectly normal and common objects of study for many disciplines today, mainly in the medical and natural sciences. Since cells are now generally considered and understood as objects in and of themselves, but still seem somewhat abstract and elusive to the general public, they also make a good object of study for ethnologists and other kinds of cultural scientists. Foetal cells are a good example of the will to manipulate biology and make it work for us in healthcare and in medicine. As such, they may shine a light on transformative processes in society concerning our perceptions of health and illness, life or death and the borders of the individual, as well as expectations and responsibilities of patients and health care. That foetal cells enable investigation into such broad – yet still profound – areas of human life, is what made them so alluring to me.



**Chapter I:** How may foetal cell therapy be understood as a phenomenon producing meaning and knowledge - different expectations, emotional effects and ethical deliberations – in patients, relatives, researchers and non-affected?

**Article II:** How is the trial organized in time and space in order to produce a homogenous and mobile bio-object like cell suspension? What scientific and ethical consequences are produced by the negotiations and compromises needed?

**Article III:** How are ethical dilemmas uncovered in tandem with the transformations of foetal cell suspension, in everyday professional practice in the trial? How do researchers express and handle them emotionally and cognitively by discursive strategies? What meaning and knowledge is produced?

**Chapter IV:** How can the production and communication of different kinds of value, meaning and knowledge in the making of a bio-object (such as foetal cell suspension) in a professional cross- or multidisciplinary research setting, be understood and explained? How can the diversity of these cultural products be further utilized in this same setting? What role may ethnographers and ethnologists play in facilitating this utilization?

The foetal cell suspension as phenomenon may aid investigation of issues of profound ethical and cultural character in the mundane tasks and technicalities of everyday laboratory life, as well as in lay and patient discourse. The concept of bio-objects (Vermeulen et al., 2012) will be developed and applied to foetal cell suspension as a phenomenon in the introductory chapters of this thesis. It should be noted that the foetal cell suspension is not adressed as a bio-object per se, in the separate articles and chapters. Still, they are to be understood as such in the broader framework that this introduction offers. The concept of bio-objects will here be explored as a central culture analytical concept with possible applications in ethnology as well as in cross-disciplinary research, as it may help in making some relatively opaque knowledge processes more transparent. This is vital, as these processes shape and interact with cultural perceptions of the human embryo – as a source of vitality (Rose, 2008) and of hope, as well as an inviolable symbol of life (Morgan, 2009).

## Disposition

The main character in foetal cell transplantation research, as well as in this thesis – the human embryo – has been introduced. The cell laboratory, which is one of the most central scenes for this investigation, has been briefly addressed. This and other key locations will be revisited later. The **Theory** section revolves around binding the roles and functions of the foetal material and the cell suspension together – with each other, as well as with tendencies concerning ethics and politics in regenerative medicine in general. Primarily conceptualizing the subsequent foetal cell suspension as a *bio-object* with transformative properties in the thesis, provides an overarching framework for understanding it as a border-crossing phenomenon of knowledge, materiality and of life. This is crucial in order to make sense of the processes it sets in motion in the laboratories as well as outside. The specific theoretical perspectives central for each chapter or article should rather be seen as tools used to explain and visualize expressions of certain cultural products, produced along with the foetal cell suspension, in context. They will be discussed briefly where the articles are presented.

After having delved into some overarching theory, the implications of **Methods** and **Empirical material** and their relations to theories and analysis are addressed. Thereafter, it is time to revisit and move into the laboratories, in the section called **Ethnographic prelude**. This is where the foetal cell suspension is manufactured, and later by many transformational steps made into data derived from animal models. This is an ethnographic section giving some researcher presence. This section offers readers a possibility to connect for themselves the descriptions of the production(s) of the foetal cell suspension to the philosophical and methodological premises, as well as to the theories employed.

In **Previous research**, studies concerning different conditions of producing as well as problematizing knowledge in a macro- as well as a micro-perspective will be addressed. Studies from ethnology as well as from other disciplines will be discussed. The first sections address **Knowledge in and of the laboratory**, while the second focuses on **Knowledge in ethnology**. The third and last section is called **Crossing boundaries and creating knowledge with bio-objects**, and addresses

how diverse previous research has culturally conceptualized the regenerative use of human bodily material in medicine. These sections present work that has been influential in the field of research and for the research style applied here – and different perspectives on scientific objects (or phenomena) comparable to the foetal cell suspension.

With some insights into the empirical field in which my studies have been undertaken, as well as some context of the study established, the **Presentation of articles** has been reached. Here, the four articles and chapters will be presented and briefly discussed in relation to the research question they target. In the final section, **Contribution**, the articles and chapters will be contextualized and discussed in relation to the aim of the thesis as a whole. The section concludes with a discussion of the overarching contribution of the thesis to the field investigated. To conclude, the focus is put on how a ‘diffractive ethnography’ can be considered an ethics-in-practice valuable in cross- and multidisciplinary settings, as well as to ethnology itself as a discipline.



# Theory, methods & material

## Presenting perspectives

The topic of this thesis is, on a theoretical level, the simultaneous transformability, flexibility and durability of objects. The foetal cell suspension is one example of such an object. Each chapter or article presents one aspect of foetal material or foetal cell suspension as products or potentials. They therefore use theoretical tools adapted to describing and problematizing these specific expressions and circumstances. Still, there is need for a more general understanding of the foetal cell as a *produced* as well as a *productive* scientific object in communication with surrounding society, which is what these introductory chapters provide. The present theoretical section adds an overarching conceptual framework to understand the different expressions targeted in the separate articles and chapters from.

Considering the refined cell suspension as a *bio-object*; a biological artefact, will enable connection of the socio-cultural effects it has to tendencies in society at large, concerning the ethics and politics of regenerative medicine. The concept inevitably challenges notions and borders of life and death and of health and illness. As such, it will help the reader to understand how these objects intermingle with social, cultural, economic, and technical aspects of developments in regenerative medicine – in the present as well as historically. The bio-object may also help visualize the interdependency of technical innovation with material conditions and cultural norms about health and the body. It does so by pointing to the contextuality and processuality of knowledge production that shapes the utilization and conceptualization of shared objects such as aborted embryos and foetal cell suspension. This theory can also account for how processes

of perceiving and conceptualizing the object in turn influence knowledge production. But in order to understand the refined cell suspension as a bio-object with certain agency outside the laboratory, we need to understand it as emerging out of the embryo as a *boundary object* for different scientific communities of practice, as well as for other groups. It is, nonetheless the practices that transform the material from one thing to another, which is the focus of this thesis.

### Boundary objects

The embryonic tissue or material may too be considered boundary objects for the different disciplines involved with them (see e.g. Williams, Wainwright, Ehrich, Michael, 2008). The concept is an important tool in understanding the relations between things, artefacts and classifications in any knowledge or information system. Within different communities of practice (Lave and Wenger, 1991), meanings of things are negotiated. This negotiation proceeds from the flexible but durable arrangement that the boundary object is (Star and Griesemer, 1989:393; Bowker and Star, 1999:297). The compromise of meaning unavoidably leads to a relative stability in meaning, which strips away the ‘anthropological strangeness’ and historical context from an artefact. This naturalization builds over time in the co-use of certain objects within these communities (1999:299). A non-questioning relation with certain objects within a group of people is also the basis for legitimate membership of a specific community of practice. Boundary objects “inhabit several communities of practice and satisfy the informal requirement of each of them” (1999:297). And, as will be illustrated with the help of foetal material, as the communities overlap, the meanings of the common objects may diverge as well as converge. Even before the embryo is made into foetal material and then refined into a cell suspension, it has been in contact with different professions and people to whom it has different functions, goals and meanings. The aborting woman may have experienced it as an unwanted potential biographical life, and materially no more than a lump of cells. Or, she may have looked at it as a potential living baby, which for reasons unknown to us could not be realized. Different reasons may render the

embryo different to her. To the abortion nurse, these cells may have been considered biological waste to be destroyed. If the abortion nurse, on the other hand, was involved in e.g. this trial, s/he would be responsible for asking the aborting woman to consent to donation. In the event of agreement, the nurse would then instead (professionally) view the embryo as donated tissue with an inherent regenerative value of vitality. This latter conceptualization is also the dominant one in the cell laboratories and the facilities of this trial. As different as these conceptualizations are between the different professions and contexts, communication across communities of practice is still possible due to the flexibility of the embryo as referential to an object and to the common interest and investment in it by the communities.

The foetal material may materially be *either* a lump of cells or an intact embryo – depending on where it travelled from – when it reaches the cell laboratory. Still, a common categorization, allowing the materiality to be flexible, labels it foetal material; a raw material to be refined into cell suspension. The practice of common labelling takes away some of the conceptual ethical charge from the embryo. It becomes naturalized (Bowker and Star 1999:299) as a scientific object in this community of practice, so that it is no longer recognized as an interrupted potential biographical life, or as human remains to possibly be mourned and buried. The invisible foetus in foetal cell research is partly due to shared but overlapping classification systems and to the boundary role of the embryo between practices. When it is turned into a bio-object, as will be elaborated on more below, the embryo vanishes, materially as well as conceptually. The disappearance of the embryo is largely due to the practical handling and refinement of it, but there are other reasons too. The woman's right to choose abortion is a prerequisite for producing cell suspension from aborted embryos. Therefore, defining the aborted embryo as foetal material, or using different but interchangeable definitions of the same material (further development of this in article III and chapter IV) in the informational system of this community of practice is making the aborted embryo a residual category (Bowker and Star, 1999:300f; 2007). It is also naturalized differently in multiple communities. As these different knowledge systems meet, they momentarily become unstable in regards to

what the embryo or the foetal material is, or means. Some meanings diverge from the same concept, while others come from different concepts but converge in the material foetal object.

The relation between the embryo and the aborting woman exemplifies one sensitive area (Williams, 2003; Kent, 2008; Pfeffer, 2009), which regenerative medicine has to navigate with residual categories as a result<sup>13</sup>. There are of course other areas in which the unavoidably politicized character of medicine becomes visible. There are many examples (outside the scope of this thesis) of how normative conceptions influence – or rather even make the basis for – the categorizations that are possible and which are not, in knowledge or information systems. The conceptual and political relation between the aborting woman and the embryo, in itself makes an argument for using the concept of boundary objects as an analytical tool in visualizing and understanding the knowledge work related to the making and using of foetal cell suspension and in analysing medical categorical work (Bowker and Star, 1999:310f) in general.

## Bio-objects

Once the aborted embryo – or the foetal material – has been refined into cell suspension in the laboratory, it has lost some of its visually obvious connections to embryos and aborting women. The cell suspension clearly has a name, a label. Still, it is known within very few communities of practice, which means few share the knowledge and use of it. The material and conceptual transformation of the embryo and of the foetal material has been turned it into an object with new agential qualities. It now has

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<sup>13</sup> The embryo cannot be allowed a subjective story for two reasons; first of all because it would circumscribe the woman's right to choose abortion; and second, because it would illegitimize cell harvest and refinement, and render it exploitative. The reasons and consequences for putting aborted embryos in a residual category need to be considered. For the trial, the main function is to make the foetal material available for use, even though it is ethically sensitive. Still, in order to not run the errands of the pro-life movement by labelling aborted embryos residual, and thereby implying that they are a politically oppressed category bereft of a voice for their lived experience, I believe that this labelling may also be considered strategic. And by that I mean that aborted embryos need to be put in residuality in order for aborting women *not* to be put there, socio-politically.



the ability to act and make a difference to its surroundings, from a culturally rather unspecified and unknown state of existence. As the foetal material is broken up into cell clusters and subsequently refined into cell suspension, it becomes a bio-object in research and in medical trials. Considering the foetal cell suspension a bio-object opens it up for investigation as an object enabling change, transformation and production outside the laboratory as a biological artefact. It makes a resource of vitality mobile between different places, biological hosts and times. It is based on the ending of a potential biographical life to the benefit and possible prolongation of another.

The sociology scholars of technology and science, Niki Vermeulen and Andrew Webster, together with Sakari Tamminen, social psychologist and social anthropologist, co-edited the comprehensive volume *“Bio-objects: Life in the 21st Century”*, dedicated to developing, explaining and expanding on bio-objects and their enactment – in practice as well as in theory (2012, Eds. Vermeulen, Tamminen and Webster). They suggest understanding the socio-cultural-material process of creating transitional, or liminal, objects of vitality in the natural and medical sciences, by conceptualizing it as a process of bio-objectification. The approach entails taking into account how different life forms are brought into existence and given sometimes multiple lives and forms, as well as how they are disentangled or entangled with other life forms, or conserved and disrupted (2012:2,5). It is by a process of bio-objectification that the aborted embryo can become a cell suspension and a regenerative transplant in the human brain, invisibly entwining hopes of patients with visions of researchers, aborting women with cell laboratories and transplanted rats, transnationally. As bio-objects are “epistemics, ontics, temporality and practice in a material wrapping” (Eriksson, 2012:27), it is also of great interest how both time and space are managed in order to make the foetal cell suspension emerge, as well as what actions, emotions, affects, understandings and explanations it sets in motion.

Vermeulen makes a point of the fact that the process of bio-objectification in itself transforms the organization and relations in and of science by changing the relations of life (2012:183). Looking at recent decades’ general developments in life sciences, we can see that this statement holds true and even extends to the organization of care. The

development of assisted reproductive techniques (ART) made us view life differently, in utero as well as in vitro and in vivo.<sup>14</sup> The unborn foetus turned into a potential treatable patient as well as an imaginable baby to come, with the introduction of prenatal sonograms in maternity care (see e.g. Barad, 2003; 2007). These developments also turned the mother-to-be into a patient to a higher degree than before. Deviant pregnancy experiences or events were pathologized, as a specialized maternity care grew broader, more technically advanced and intervention-prone. In vitro fertilization (IVF) is an important part of ART today, and is also the main source for the development of human embryonic stem cells (hESC). These spare IVF embryos can therefore be seen as functioning as bio-objects that enables and activates large reorganizations in regenerative medicine, when they start being used to create stem cell lines for therapeutic and research purposes in regenerative medicine. Umbilical chord blood (UCB) is another example of such an object and a source of stem cells, which has received some attention lately due to ethical issues about consent given for their collection, as well as for the banking procedures involved.<sup>15</sup> Transnational UCB banking requires vast networks of facilities, records as well as staff and patients – or clients. The bio-objectification of UCB also alters socio-political as well as economic relations, as it may e.g. be a competitive advantage catering to the needs of ethnical minorities, even if it renders less profit or compensation for the individual actor. The complex process of genetic matching required in UCB makes it a transnational, cosmopolitan endeavour on the borders of public and private (Brown, 2015). The innovational steps taken in order to harness the vitality of UCB will then in turn start new technical, legal, ethical and socio-cultural transformations in society.

As the examples above have demonstrated; bio-objects are allowed agency from a state of existence often lacking a common definition – provided they deliver on the promise of therapeutic value they often

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<sup>14</sup> In vitro literally means in glass, in a petri dish. In vivo means within a living organism.

<sup>15</sup> Umbilical chord blood is usually collected directly after the birth of a child, and the mother's consent is usually considered surrogate for the infant's, and sufficient for legitimate collection as well as storage (Perini and Farisco, 2011).

display. Still, they enable and demand some unexpected relational transformations in society, as they often renegotiate issues of how the integrity and rights of individual persons are best protected.

## Methods

### Background

This is a study of the making, utilization and conceptualization of a bio-object, using the production of foetal cell suspension as a case. Human foetal ventral midbrain (VM) neural cells – like the ones described in the introduction – are the source of cells used in the TransEuro trial, which has been researched for this thesis. The trial is a European research consortium, funded by the 7th Framework Programme of the European Commission. The main objectives of the trial are briefly, as their website states: “to develop an efficacious and safe treatment methodology for patients suffering from Parkinson’s disease using fetal cell based treatments”, and “to develop a protocol that can serve as a template for all future clinical trials in the cell therapy field including stem cell-based therapies and the ethical implications and ramifications of such work.”<sup>16</sup>

A sub-project called ‘Ethical Governance’<sup>17</sup> was conducted before the initiation of the medical trials. Focus group interviews were carried out in

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<sup>16</sup> Sources: <http://www.transeuro.org.uk/index.html>, <http://www.transeuro.org.uk/pages/objectives.html> (Links retrieved on May 18, 2018)

<sup>17</sup> The sub-project “Ethical Governance” was a focus group study, initiated by the late Herbert Gottweis; Professor of Political Science at the Life Science Governance Institute in Vienna, Austria. The Swedish research team consisted of Professor of Ethnology Susanne Lundin (PI), Assistant Professor of Ethnology Markus Idvall and myself, all from the Department of Arts and Cultural Sciences, Lund University. The Swedish branch of the project was approved by the Regional Ethics Board in Lund (Regionala Etikprövningsnämnden). Ref. nr. 2011/575. Idvall and I used a script created by Herbert Gottweis and Ursula Gottweis, Doctor of Psychology. It described very carefully how the interviews were to be performed, and what aids and props were to be used for the right collection of data. The script had been written in English, and was translated into Swedish by my colleague and myself. It was also shortened in length and content, in dialogue with the initial author and project initiator Gottweis.

order to scout the ethical terrain of cell transplantation research in the attitudes of patients, relatives and non-affected laypeople in the participating countries. The project gave insights into the attitudes and considerations towards the research horizon of treatments for Parkinson's disease, from which to make clinical advances. As I was part of this sub-project in conducting as well as analysing the Swedish interviews, it provided me with a vast body of empirical material as well as a great foundation to build upon in the subsequent individual fieldwork. Besides the large focus group material and a couple of individual interviews with researchers, the main material has been extensive observations in the cell and animal laboratories of these researchers.

As the focus group study had been concluded and the preparations for the medical trial were about to start, some initial information and planning meetings were held with key persons at the Neurology Department of the research hospital and biomedical centre (BMC), Lund University, Sweden, in the early autumn of 2012. There and then, my individual fieldwork endeavours also started, extending into the spring of 2015.<sup>18</sup>

### Ethnographic methods; rationale and knowledge claims

The Swedish ethnologists Lars Kaijser and Magnus Öhlander state that “ethnological methods in general require a ‘pragmatic systematics’” (2011:141). While one needs to be able to structure the fieldwork and the

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<sup>18</sup> As research on professionals in their occupational roles is exempt from the rules of ethical review, the regional ethics board has not reviewed my individual research. (Source: [http://www.ht.lu.se/fileadmin/user\\_upload/ht/dokument/Fakulteterna/policydok\\_planer/Lathund\\_for\\_etikprovning.pdf](http://www.ht.lu.se/fileadmin/user_upload/ht/dokument/Fakulteterna/policydok_planer/Lathund_for_etikprovning.pdf), link retrieved October 30th, 2018). However, continuous reflection on ethical issues or dilemmas have been a necessary and important part of the research process. There is no way of entirely escaping our own unique, individual predispositions and modes of action – and in my view, nor is it desirable. Just as I cannot give a full account of the intentions of the researchers I study, nor can I fully grasp and retell the conditions on which they act. Nor can they, obviously, fully fathom mine. Therefore, I believe it is of the essence to try and keep my own voice as visible as possible – in fieldwork and interaction as well as in accounts – so that the reader can discern the voices of others. To aim for sincerity through transparency (Davies, 1998:242; Tracy, 2010:84off) and to keep in mind the partial, situated and incomplete knower (Haraway, 1988; Davies 1998:265) are healthy guiding principles.

constructed material for analysis, one also needs to be able to be flexible to circumstantial changes in the field, and to gradual changes in knowledge aims, as one's insight into the field or phenomenon studied expands and deepens.

The methods used for creating the material for this dissertation are exclusively ethnographic methods. The first phase of this – as of much other ethnographic work – may be characterized as inductive. In it, all situations or materials related to the genesis of the foetal neural cell implant were viewed as informative of, as formative for, the thesis project. This meant that journal articles on the history of cell replacement therapy in Parkinson's disease, as well as suggestions for protocols of cell preparation for the trial, and informal discussions on these same protocols, could be considered empirical material. This approach allows for creating a vast basis of information and understanding, well suited to ask more specific follow-up questions to material as well as to participants. It allows patterns to emerge, often giving clues to important events and activities. Such a *modus operandi* is common in qualitative research: hypotheses of sorts are created during material gathering and the first tentative analysis, then further investigated, tested and either confirmed or rejected in the research to come. Hence, a deductive element is nonetheless present, but not prior to the inductive phase. The newer material is interpreted in the light of the older, but the analysis that came out of the older material is contested in the light of the newer. This is a standard process in ethnology and in many other disciplines of the humanities, and this was the general order of events also in process with this thesis. These methods require the researcher to 'be there' (Frykman and Gilje, 2009), in order to reach into practices in the situations in which they occur. Important insights or analyses that are not being verbalized in the setting, can be lifted and discussed in interviews with the participants later. This enables reflection on the part of the researcher in the laboratory, and may give a broadened as well as deepened common understanding of the events. Therefore, this study was designed and conducted this way: to chronologically start with observations and follow up with interviewing the researchers.

The main types of ethnographic methods used for the thesis are focus group interviews, observations and semi-structured interviews, all of

which will be discussed in more detail in relation to the material they rendered, after the empirical materials have been presented later in this section. The analysis has been qualitative, using diverse materials such as texts in the form of processed and formalized protocols or transcribed interviews, of field notes as well as photographic material from observations. The material constructed and analysed from the work in the field is mainly from one single medical trial. However, as the thesis conceptualizes the foetal cell suspension as a bio-object emerging from the process of transforming diverse embryonic material into homogenous transplantation results, three things may be noted. First, the procedures investigated are supposed to be homogenous over the participating sites; second, the point of departure of the thesis is that they can never *completely* be! As my study relates and compares to other kinds of laboratory studies and similar research on the use of human and/or embryonic tissue, it makes it possible to discuss the ways in which the scientific rationale – as well as the results of these studies – resonate alike or differently. Third, it may be that while the cultural products described as brought forth in the chapters and articles are specific, the mechanisms of the bringing forth and the rationale behind them may be somewhat more general. It is these mechanisms that the concepts of boundary object and bio-objects are meant to conceptualize and discuss.

In the ethnologist Helena Petterson's thesis, the concept of research and the role of the researcher in themselves work as boundary objects for her and her participants (2007). In my research, I had the same object of study as my participant researchers: the foetal tissue and the foetal cell suspension. This made it work, not only as a bio-object, but as a common boundary object for us. In that respect, our research can – as discussed earlier – in a sense be said to be multidisciplinary. Still, our knowledge aims as well as claims to the cell suspension differ. They want to know how to best make it homogenous, mobile, safe and effective, while I want to research reasons other than strictly scientific one for rendering the cell suspension in a certain way, and what consequences – other than cell-biological – that rendering has. My attempts to answer both the how's and the why's also extend in many different directions, while their attempts are mainly unidirectional. They want their actions to have the right kind of

consequences. No matter whether I manage to give a truthful account of events and relations leading up a successful (or unsuccessful) cell suspension, it does not in any way imply that I have a successful account of how the intentions of the researchers help further their goals (Faye, 2012:67). However, I can investigate their understanding (or, interpreted meaning) of the conceptual cell suspension by examining their intentions, which are subsequently reflected in their actions directed at the material cell suspension, independent of the outcome. Basically, this is what I have done in my fieldwork.

The combination of materials and the approach towards them as discussed above, may be called a ‘bricolage-assemblage’; a concept that is related to but not equal to ‘bricolage’. The latter mainly refers to the combination of diverse methods and sources in qualitative research. The bricolage may support one single theory or thesis, but may also work to rather complicate the picture (see e.g. Jönsson and Nilsson, 2017:8, 67). The concept of ‘bricolage-assemblage’, however, is rather about what the account – the ethnography, the product – enables. Diverse methods gather diverse materials and create a new combination of knowledge that makes new realities possible. The combined concept borrows ‘the assemblage’ from actor-network theory to point to the different materials as gatherings of actors that make new relations possible (see e.g. Latour 2005:43ff). Using this metaphor to think with, there is no sharp theoretical distinction between discourse – what is said, how it is said and by whom – and matter, material manifestations and processes, in what they can enable or bring forth. Rather, the quality, significance and role of what is being brought forth by either speech, gestures, text or materializations to the studied phenomenon – in this thesis the foetal cell and the suspension – decide the mode of analysis used and the importance ascribed to the different materials. In a sense, this approach also makes theory and method converge too, since it acknowledges how methodology in itself influences knowledge production as much as theory. Each contribution to the empirical bricolage – no matter what the format – is always understood in relation to the studied phenomenon’s larger societal context. This approach sees the knowledge produced in this study as an ontological category itself in becoming, in much the

same way as the foetal neural cell is an ontological category in becoming – yet unstable and contestable. This will be more philosophically explored in the section *A diffractive approach* below. However, as a practical ethnographic and ethnological method, the approach can be developed with the methodological perspective of crystallization.

## Crystallization

One methodological metaphor stemming from natural science employed in qualitative research is *crystallization*. The concept is often used to describe the practice of using multiple theoretical perspectives, methods or diverse sources and materials in order to illuminate a problem or phenomenon from many different angles. Just as a crystal refracts the light that passes through it in different directions and into different colours, patterns and arrays (Tracy, 2010 on Ellingson and Richardson), so does a specific methodological tool, theoretical perspective or a material enable different accounts and perspectives on a certain phenomenon. In a methodological sense, the foetal cell suspension has worked as a crystal or a prismatic object in this study. It has been as much an object of study in itself, as it has been a methodological tool to extract/diffract/refract perspectives, emotional responses and experiences that it sets in motion in different settings and individuals. By using a bio-object like foetal cell suspension as a conceptual lens to diffract meaning and materializations from the different empirical materials – such as focus group interviews, observations, documents and individual interviews – an entangled pattern of light and darkness arises. The pattern makes it possible to trace how the concepts and hopes of the researchers in the laboratories resonate or dissonate with the expectations of the patients, as well as with the requirement of a standardizable foetal cell suspension.

An allowing and experimental methodological approach is, as mentioned above, quite common in ethnological fieldwork practice. Even if not always conceptualized as crystallization per se, they arguably have some traits in common. The concept of triangulation is often used instead when describing the process in which different materials, methods or theories are used to illuminate a certain problem from different perspectives in



order to create a large body of diverse knowledge (Kaijser and Öhlander, 2011). Traditionally, however, the purpose of triangulation is that the combined approaches are meant to support the *same* results – not that different combined approaches generate *different* results or analyses (Tracy, 2010). No matter what labels used, the generation of partial truths and accounts is thought to offer a fuller and richer understanding of the object of study. This approach stands in stark contrast to the general modus operandi of natural sciences, in which a greater number of studies supporting a specific outcome is always desirable. However, this thesis rather wishes to bring out difference and diversity of knowledge. For these purposes, crystallization as a method harmonizes well with a diffractive approach.

### A diffractive approach

Acknowledging as well as embracing the located, incomplete, situated and partial knower (Haraway, 1988) is at the heart of the texts of the feminist physicist Karen Barad (see e.g. 2003, 2007) and her theory of agential realism (2007:185). On one hand she draws heavily on Danish physicist Niels Bohr's interpretation of quantum physics, and on the other on the theories of situated knowledges and partial perspectives of Donna Haraway (1988), discussing the power structures active in knowledge production. Another important pillar in Barad's reasoning is the performativity concept, which Judith Butler established during the 1990s to explain expressions and reproductions of gender and of sexuality (1993). Fusing these lines of thought, she offers an understanding of the world as enacted socio-materially as complex phenomena, built by incomplete accounts and experiences, as much as of subatomic particles all acting in entanglement. These entangled phenomena are then interpreted and explained within the analytical frameworks that theory, norms and scientific equipment can offer. The processed accounts of the phenomena, such as results, opinions, categories and charts (scientific or other), are viewed as diffractive products.

Diffraction is a concept originally taken from physics, which explains what happens when a wave encounters an obstacle. It was first explored in relation to knowledge production by Donna Haraway (1992:30). Barad

uses a handful of vivid illustrations to describe what diffraction is and what it produces socially. I will here turn to the example of interfering ripples in a pond (2007:76f). If one drops two stones in a pond, two patterns of ripples will occur, and they will interfere with one another, and be called an interference or diffraction pattern. Rather than taking an interest in the reflecting surface of calm water, Barad takes looks for the water with multiple ripples in interference and with raging waves. She also uses the concept of ‘diffraction’ to present an extension of – or maybe an alternative to – the reflexivity discussion within social and cultural sciences, which she says is founded upon representationalism. “Reflexivity, like reflection”, she says, “still holds the world at a distance” (Barad, 2007:87). It “displaces the same elsewhere”, in Haraway’s words (1997). Barad states that “diffraction is not about any differences, but about the differences that matter” (2007:378). The differences that matter concerning the foetal cell suspension are the ones that make us understand and relate to it differently. For some of the researchers in the lab, it is mainly a solution with some free-floating cell clusters with the ability to embed in another brain, but it can also be a vehicle into an academic career<sup>19</sup> (Hansson, 2017). Throughout their trajectory to becoming a bio-object, the cells have set different social and material processes in motion. Each article and chapter in this thesis investigate a cultural product that is co-produced with the cell suspension, but that is located outside the scope of the medical trial itself.

To clarify how this is to be thought of in the practice of doing research, Barad uses an example once suggested by Bohr to explain how our interactions shape phenomena: “If a person in a dark room holds a cane, they can intra-act with it in two mutually exclusive ways. By holding the cane firmly, the person can use it to navigate the room. The cane essentially becomes an extension of the subject. If the person instead holds the cane loosely, its features can be examined, turning the cane itself into the object

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19 For the afflicted patients, it can be the hope of a better future and maybe a longer life. For the aborting women it may provide a way of creating meaning around an otherwise often culturally ambiguous and reproductively ‘meaningless’ event. It can offer an opportunity to give value to their foetal waste. For the researching ethnologist, the cells present an opportunity to map out different possible understandings and enactments that the foetal cells enable.

of study” (2007:154). Holding the cane – or rather the foetal cell suspension – loosely, it becomes the object of investigation and the researcher will diffract knowledge from it. Holding the foetal cell suspension tightly, it enables the researcher to instead use it as a tool to explore its surroundings. This allegory resembles the ways in which I have employed the concept of the foetal cell suspension itself also as a methodological tool. Holding it loosely, it is the concept of foetal cell suspension itself that is examined together with the researchers in the laboratories – or with patients, relatives or non-affected. Holding it tightly, we use it together to explore the borders of their respective socio-cultural space time; being either the trial, the local laboratories, regenerative medicine in general or the lived experience of being a patient with Parkinson’s disease, a relative or a citizen thinking of regenerative medicine and the use of foetal cells. Methodologically, it’s about tightening or loosening one’s grip.

## Empirical material

The time has now come to clarify what different materials, or phenomena, were diffracted in fieldwork. The material will first be presented in a short list, and then elaborated on by category – considering the conduct, context and conditions of composition. In short, then, the products of the process consist of the following material:

- A compilation of approximately 25 national as well as European Union level, documents guiding the trial practically, ethically and policy-wise. These ranged from ethical permits to good clinical practice (GCP) and standard operating procedure (SOP) descriptions.
- Approximately 250 handwritten pages of field notes, comprising mainly observations in the laboratory, but also in meetings of the regional board and the planning group. The notes also contain my own reflections and analyses.
- In verbatim transcriptions of six focus group interviews, focusing on experimental research on Parkinson’s disease, particularly cell therapy development. The interviews had a duration of about 2.5 hours each, and a mean of five participants.

- In verbatim transcriptions of two interviews with junior researchers Emma – who works in the cell laboratory, and James – working in the animal laboratory<sup>20</sup>. The focus was on the roles of their specific tasks in the cell transplantation trial in relation to overall aims, and the relation between the conceptuality and the materiality of the foetal cell. These interviews – which mainly focused on the activities of these same researchers – complement and enrich the observations in the laboratories by commenting on and problematizing them.

Exploring processes and practices of producing bio-objects is crucial for better understanding cultural mechanisms and phenomena embedded in biomedicine. This understanding is relevant to society and in need of further and continuous conceptualization. My contribution to that aim is this culture analytical study of one participating site in a cell transplantation trial, with the main focus on their processing of foetal material into a transplant, a cell suspension. The material constructed and analysed in and for this thesis is arguably not very large, but rather detailed concerning scientific terminology, process, aims and challenges. By taking the minutiae of the process into serious cultural and philosophical consideration, it may be possible to construct more transparent knowledge of an activity surrounded by a parlance and a terminology often conceived of as alien.

## Observations in conference rooms and laboratories

The observations started spring 2013, with the possibility to participate in the regional TransEuro planning group meetings. These were held on a regular basis every one or two months in the same conference room in the biomedical centre. There, information was shared on progress, obstacles, delays and issues shaping the participating sites common moulding of homogenous cell suspension. Observing at these meetings mainly consisted of listening and taking notes. Dates were planned there for so-called dry runs – in which the researchers practice the procedures before transplantation to patients<sup>21</sup> – and other tests. Explanations of what led to

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<sup>20</sup> Emma and James have been given aliases for confidentiality reasons.

<sup>21</sup> A fuller description and explanation of the concept will be given in the chapter “Ethnographic interlude”.

delays and why, as well as what problems seemed to define the shaping of the common scientific object, were discussed too. Sometimes the hold-up was due to problems with equipment, sometimes protocols, sometimes access, and sometimes people. I also had a chance to follow the neurobiologist Emma and a research nurse to meet a midwife at another clinic nearby, with whom the neurology department is collaborating in order to get the right amounts of foetal material. The meeting was set up in order for Emma to hand over protocols and information on procedures together with some equipment to be used.

The dry runs finally took off during the autumn of 2013. Observations in the cell laboratory and in the animal transplantation laboratories could therefore be conducted now. The observations were carried out throughout some months' time, and consisted of following Emma, who was one of my two key participants, in her work with receiving an aborted embryo, dissecting it, washing and dissociating the foetal tissue into cells in a suspension. The other participant's work took on where the first left off – as did the observations. This participant, James, was responsible for transplanting the cell suspension into the brains of prepared rats, and to evaluate the hoped-for disease regression in the living rats as well as in the sliced brains of the later sacrificed rats.

In between the crucial tasks of the researchers, a lot of informal chatting took place. Taking brief notes while observing, some questions were asked here and there when it felt suitable. These were also the instances where the chance was presented to ask more extensive questions or discuss related issues of their research or working context. This oscillation between an open and a focused mode of observation allowed for the knowledge aim at hand to be targeted, while also letting it develop and sharpen during the process and keep the knowledge aim progressive as new hypotheses formed (Kaijser and Öhlander, 2011:141). While observing in the cell laboratory, photographs were taken for later use in analysis, for complementing the other empirical material and for aiding memory in analytic work. As soon as possible after observations, a more extensive story was constructed from the field notes. To write a coherent empirical story of each occasion allowed for elaboration on perspectives and analysis. These accounts were later merged into one account and presented in the introductory chapter “Empirical interlude”.

It would in a sense be misleading as well as misguided to call the observations participatory on my part. I did not on any occasion help – or even try out – dissecting embryos, preparing cell suspension or transplanting to rats. It was a silent but nonetheless evident agreement that no such thing would be acceptable. The sole reason for me being there in the first place was my ignorance of the procedure, and the initiation rite to truly be invited to participate would be at least another five to six years of education and a contract from the research unit. Still, some practical zones of participatory interaction existed, in which I could for example help fetch an instrument or solution, or be invited to pet a rat – all with the proper protective and sanitary clothing. Sometimes I was assigned an informal role as assisting hands, but usually not. However, my presence can be said to be participatory in that I – to a high degree – was highly attentive to detail in their procedures, and therefore managed fairly well to discuss their work in a way that I experienced to be stimulating also for them.

The descriptions of the observations were made as thick as possible (Geertz, 1973). The events in the laboratories do not consist of grand gestures or obviously symbolic actions. It is also most often quiet and calm. That is in itself, of course, a relevant observation. However, it took some visits to the labs before I realized this and before I had obtained enough information and data on the procedures in themselves, to enable me to move on to consider the larger context as well as to notice the surroundings. In the beginning, the details of the procedures absorbed me fully.

## Interviews with the researchers

Having compiled the extensive observations of the different procedures, they were synthesized and analysed with respect to the crucial instances of transforming the foetal material. Connections were made between the presence of the embryo in different forms in the observations and in our informal chats, and in what was stated in documents and protocols, as well as what was being said about it in the board meetings. Having identified the different phases and instances where the foetal material seemed to be

transformed, linguistically as well as materially, two interview guides were constructed.<sup>22</sup> They had quite similar content, but were adapted to target the different tasks and subsequent aims of my participants. The interview guides were designed to make the interviewees reflect and elaborate on the practical implication of their labour in the laboratories, as well as what they perceived to be the reason and rationale behind their task in relation to the trial as whole. I used this link between practice and rationale to facilitate philosophical discourse between us concerning the value and vitality of the foetal cell, and on the ethical imperative for using or not using these cells. This allowed for their voices to be heard, and hypotheses formed during observations could be tested for their resonance with the participants (Tracy, 2010:844). A diffractive approach was applied when constructing the interview guides, in that they would to some extent enable us to search together for answers and ideas, as well as to research one another. This required facilitating a discussion in which my viewpoints and opinions on the topics were openly displayed as well (Davies on feminist interview methods, 1998:48).

The interviews were conducted during the fall of 2014. The first one was with James, working in the animal house doing transplantations. We met in a café and talked for almost two hours. This interview was conducted in English. The second interview was with Emma, who was working in the cell laboratory dissecting the embryo and preparing the cells into a suspension. They were both junior researchers in their thirties. We met in a small informal conference room in my department, and this interview was conducted in Swedish and the parts deemed relevant later translated into English. This interview lasted about one and a half hours. Both interviews were transcribed verbatim.

### Focus group interviews

The recruitment of participants with Parkinson's disease to take part in the focus group interviews went via the neurological clinic at the research hospital. The recruitment was done with help from nurses and

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<sup>22</sup> See appendix.

physicians there, who presented patients who met the trial's inclusion criteria<sup>23</sup> with the opportunity to participate. They received information on the project and an informed consent sheet which was to be sent directly to me or my colleague without passing through their treatment personnel first, if they chose to participate. Access to some more patients and also relatives of patients was gained by contacting patient organizations, and the recruitment of the non-affected people was done by word-of-mouth recruitment and by advertising in public spaces. The participants contacted this way also received information on the project and signed an informed consent sheet.<sup>24</sup> Six focus group interviews were conducted, with a mean of five participants in each, but ranging from five to eight. The interviews took about two and a half hours, with a short break and coffee and refreshments included.

The tendency in focus group interviews to either create consensus or polarization amongst the participants needs to be taken into account in conduct and analysis (Davies, 1998:117). However, this circumstance can arguably be taken advantage of if one carefully acknowledges the dynamics in the specific group (and in between different groups) and rather view the voices and opinions manifested as somewhat caricatural representations of interests and norms in society. This was taken into account when the transcribed interview material was analysed. I searched for statements and discussions that related to the embryo, the foetal cells or the particular method used for implanting such cells and related to the statements and discussions on hESC, for comparison of ethical aspects. The statements made by patients and relatives were compared by those made by non-affected individuals, and some common as well as divergent themes and aspects of them were found in between, and for, each group.

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<sup>23</sup> The patients had to be under age 68 and could not have e.g. any medical, cognitive or psychiatric disorders. They had to be previously neuro-surgically untreated and could suffer from drug induced dyskinesia (involuntary movement).

<sup>24</sup> As approved by the Regional Ethics Board in Lund. Ref. nr. 2011/575.





Figure 2: Textuality meeting materiality, instruction meeting practice.

## Document analysis

Throughout the project process, different documents such as project plans, ethical permits, protocols and instructions guiding the medical trial have been used as a kind of empirical background material. They have functioned as nodes of sorts, connecting the knowledge aims of the trial with the attitudes and strategies of the researchers, as well as with the knowledge aims of this thesis project. The documents were both European Union-level regulations and national Swedish regulations; some were internal so-called grey documents,<sup>25</sup> while others were either official or confidential. Most of them were protocols directing the research. These were, for example, ‘standard operation procedures’ (SOPs) describing how the embryos were to be dissected, hibernated and dissolved into an injection

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<sup>25</sup> Internal, unofficial documents.

fluid, the cell suspension. Acquiring SOPs from both Sweden and Great Britain allowed for comparison of how the foetal neural cell as a scientific object are produced and what measures are taken to ensure the production of a homogenous cell suspension. In analysing the documents, most attention was paid to sections where the embryo or foetal material and cells were mentioned, in what context these words appeared and what choice of phrasing described what specific material. These documents were of great value when the observations started in the laboratories, and later also in the individual interviews with the two junior researchers. The insights from the document analyses helped guide this study towards the interesting points of linguistic as well as material transformations of the foetal material in the making of cell suspension. The documents also functioned as comparative material on the theoretical process with the foetal material, and on the actual practice.

## Ethnographic interlude

So far, the reader has only gotten brief glimpses from the practice of making cell suspension, in the introduction to the thesis. This ethnographic interlude offers a more detailed account of and understanding of the skill needed as well as the equipment and material involved in the material and conceptual making of foetal cell suspension.. The schedule or work order of the TransEuro trial will first be outlined, creating a context of logic and of logistics into which the subsequent account of laboratory work with the cells may be put. But before that, some comments on the design of this ethnography.

As the articles and chapters in this thesis do not contain much lengthy ethnographic descriptions of and in field, adding a straightforward account from the laboratories studied offered a chance to give the reader an insight into the practices examined and problematized in this thesis, as well as a researcher presence (Frykman and Gilje, 2009) not always otherwise visible. The ethnographic interlude is merged from different accounts of repeated observation in the laboratories, and is kept 'clean' from theoretical or analytical elaboration. This is a deliberate choice, made on the basis that this thesis as a whole does not offer much ethnographic description, but has a rather theoretical and methodological character already. This way, the ethnographic interlude may function as a backdrop to understand the chapters and articles, as well as the theoretical perspectives offered for problematizing the foetal material and cell suspension in the thesis introduction. It is written this way so that it will successfully be able to fill these diverse functions. Still, this choice should not be interpreted as ignorance of the so-called God-trick, in which the viewpoint and viewer themselves are invisible (Haraway, 1988). As there are no objective or neutral accounts of events (Clifford and Marcus, 1986),

this does not in any way have such aspirations either. Rather, the theoretical choices, standpoints and partial perspectives (Haraway, 1988) represented, are visualized and examined at length in the chapters, articles and in other parts of the introduction to this thesis.

## The TransEuro trial workflow

The work order involving foetal material within the trial can take three different directions. It may either be a routine working day, in which cells are procured from embryos, cell suspension made and rats transplanted, while yet other rats are put down and their brains sliced up and implants evaluated. This is where and when most of the basic research is done. Surgery on patients is then neither rehearsed – as in the dry run – nor actually performed. If it were instead a practice called ‘dry run’, all the steps of the cell preparation process including tasks and logistics leading up to – but excluding – transplantation in patients, are practiced in all minutiae according to the trial’s international regulations. Even if the dry runs are carried out locally and in accordance with local schedules and routines, they are guided by documents developed within the larger framework of the international TransEuro project. If it is instead an actual transplantation day, all events of the dry run must work impeccably, and finally the cells transplanted to the brain of a patient.

Below, the three scenarios will be briefly outlined. Then we move into the detailed accounts of the practice in laboratories on a given routine working day. Some procedures are the same, no matter which is the ‘work mode’ of the day. Even if details also differ locally between the participating sites, it is generally performed in the following order: After an aborting woman has consented to donate her embryo, the abortion is carried out at the facilitating clinic or hospital. The embryo is collected, either by curettage in surgical abortions, or with a vessel collecting the aborted tissue, in the case of a medical abortion. A midwife takes care of the embryo, washes and hibernates<sup>26</sup> it and sends it in a sealed vessel to the

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<sup>26</sup> Hibernation is a state of metabolic depression. In cell biology, a certain solution is used to achieve this state on a cellular level, to hinder development and proliferation of cells in vitro.

cell laboratory. There, it is dissected and the tissue is washed, dissociated into cell-clusters and further hibernated. What remains is a cell suspension that is taken to the operation room in the hospital, in which – on a surgery day – an anaesthetised patient, or trial subject, waits prepared for the surgery. A hole would then be drilled into the patient’s skull; the dura mater – a thick membrane covering the brain – punctured; and a needle inserted at previously calculated index points<sup>27</sup> in the dopamine-producing substantia nigra region of the brain.

If it is neither a surgery nor a dry-run day, but rather a routine working day of the project, the cell suspension is instead used in data generating basic research. The cell suspension is then taken to the animal house, to be transplanted into anaesthetised rats, in which Parkinsonian symptoms have been induced by incisions to the brain. Their recovery and symptom reduction will first be evaluated while alive. After six weeks have passed, the rats are sacrificed, their brains collected, sliced, put on glass slides and digitized – and the transplants evaluated and made into data.

Once good enough results have been reached in the transplantations to rats, and once the cell laboratories start receiving enough foetal material to cover the amount needed, transplantation to Parkinson’s patient candidates will begin. The candidates have volunteered and been formerly selected based on age, disease progress, and cognitive and mental abilities. The volunteers go through a number of physical as well as mental tests on and off their medication, in order to assess their suitability for participating. As there is consensus among the researchers that younger patients with less severe symptomatology have a greater chance of clear beneficial results, as well as greater recovery, they are the target group for these transplants. Preparing to receive the actual trial candidates for transplantations, the trial surgeon rehearses the transplantation process. Together with parts of a team, the surgeon prepares all the equipment and rehearses different routines. Simulation of the transplantation process, as well as an evaluation of allocated time slots for the different activities, is done.

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<sup>27</sup> These calculations are done with the help of MRI scanning of the patient’s brain.

In the sections to come, we will follow the two researchers, Emma and James, into the cell laboratory and the animal transplantation unit, on what could be an ordinary working day. It is the researchers in these locations that have the most intimate and prolonged contact with the cell suspension and its precursor, the foetal material. It is arguably here that the majority of the work of transforming and producing the foetal material into cell suspension takes place. But before that can happen, the embryo needs to enter the facilities.

## Constructing the cell suspension in praxis

The embryos often are delivered from the nearby abortion clinic to the biomedical centre (BMC) by taxi. Today is no exception. As they arrive and we receive the sealed and cooled vessel, Emma collects it and we walk together to the clean room. We change clothes and disinfect in the adjacent airlock room. As we enter there is sharp, white lighting from fluorescent tubes, facilitating an easy overview of all the surfaces and equipment. The lab room is very quiet and free from odours. There are air flow hoods, microscopes, incubators and cell counting machines<sup>28</sup>, as well as smaller instruments for dissection, pipettes, tubes and disposable gloves in different drawers and boxes marked for the purpose. Once you get used to the environment and the relative quiet, you will notice a kind of muffled murmur from what I guess is either the ventilation system or the incubator. Emma starts to prepare the paperwork as well as all the instruments and the different solutions (see figures 3 and 4). The protocol for making the cell suspension is fairly new to her, so she spreads it out on top of one counter in order to be able to check each step properly before and after performing it. She fills in the form that makes each embryo used in the trial traceable by an ID number. Its size and estimated age is documented.

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<sup>28</sup> The stainless steel working benches covered by glass hoods are called air flow hoods. The name refers to the built-in ventilation system. The incubators are storages keeping petri dishes and tubes with organic matter, cells or liquids at the right temperature and humidity for either growing or maintaining them.



Figure 3: One container is marked “TransEuro”. Labelling is important for keeping order in work, as well as in culture.



Figure 4: Preparing the procedure. Liquids, solutions and containers make up a large part of the material knowledge construction in the laboratory, when producing foetal cell suspension.

## Dissecting

Emma concludes that one of the two embryos is far too small and underdeveloped, just as the clinic had already warned them. The other one, however, is usable as it is estimated to be nearly nine weeks of age, and Emma gets to work preparing the dissection of it. She prepares a hibernation<sup>29</sup> solution in the petri dish in which the embryo will be dissected under microscope. This solution will stop the cells from dividing and developing further. She mixes it with a drug that helps cell survival and then places the embryo in the dish.

After doing this, Emma takes a sample from the hibernation medium in which the embryo has been transported, who will be sent to another laboratory to test the tissue microbiologically for sexually transmitted and other disease. Another form is filled out and the tissue is given yet another ID in order for it to be traceable outside the project (see figure 5). She puts the dish with the embryo under the lights of the microscope and starts removing the head from the rest of its body (see figure 6). To help guide her, there is a monitor connected to the microscope, showing to her and to possible bystanders what happens under the lens at a larger scale. Emma continues to remove tissue from the head with the help of small tweezers and scissors until only a small, faintly white tissue remains. This is the mesencephalon, or midbrain, in which the cells that will later be dissociated and made into a suspension reside.

## Checking cell viability

When the tissue is properly dissected and washed six times, she takes a small sample from it and dyes it with a blue liquid called Trypan blue (see figure 7). It is a kind of dye that colours the core of the already dead cells, making it possible to decide the viability of the preparation. Emma draws some of the now blue liquid from the tube with a pipette as a sample for checking cell viability. Once the check is done, the entire sample must be disposed of, since the dye is very toxic. If the sample is

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<sup>29</sup> Hibernation is a state of metabolic depression and inactivity.



viewed in the microscope, the dead cells are visible as blue dots. To get a count of the amount of cells alive, which is important in the trial, this special slide is inserted into a machine called ‘The Countess’ (see figure 8). The Countess informs us that the tissue tested has enough cells alive to be used for transplantation; it is viable. However, the tissue will first need to be dissociated and made into a suspension. This procedure is planned to take place in a couple of days, and until then the tissue will be kept hibernated and refrigerated, in order to stay fresh.

The image shows a medical form titled "Remiss Mikrobiologi" (Referral Microbiology) from "Medicin Skåne Remiss Mikrobiologi". The form is partially filled out and has two barcode labels with the number "9542854". The form is divided into several sections for different types of tests:

- Öra-Näsa-Hals (Ear-Nose-Throat):** Includes checkboxes for "Provmaterial" (Nasofarynxsekret, Svalgsekret, Hörslöngssekret, Sinussekret, Tracheal / bronkial-sekret, Sputum / CF, Sterilt borsprov (bronkialt), Bronksköjvåtska (BAL)), "Önskad undersökning" (Legionellaantigen, Pneumokockantigen), and "Vårdhygien / Smittskydd" (Personal, Patient, Anhörig/kontakt, Vårdort/triksområde skall anges i anamnesrutin ovan).
- Urinvägar (Urinary Tract):** Includes checkboxes for "Provmaterial" (Urin mittstråle, Blåstid, Kateterurin, Blåspunktion), "Önskad undersökning" (Odling, P-fimbrier), and "Vårdhygien / Smittskydd" (Legionellaantigen, Pneumokockantigen).
- Genitalprov (Genital Test):** Includes checkboxes for "Prov från" (Cervix, Uretra), "Önskad undersökning" (Odling), and "STI-diagnostik" (Prov från: Urin första portion, Urin + vagina, Cervix, Uretra, Rectum).
- Tampopatogener (Swab Pathogens):** Includes checkboxes for "Provmaterial" (Faeces).

At the top of the form, there are fields for "Patient ID och Namn" and "Patient ID ej styrkt". The form also includes a section for "Antibiotikabehandling" (Antibiotic Treatment) with checkboxes for "Immunsupprimerad", "dravvt", "Blodsmitta", and "Hälsokontroll".

Figure 5: Traceability and anonymity. Testing the cells for disease protects patients from contagion and donors from exposure.

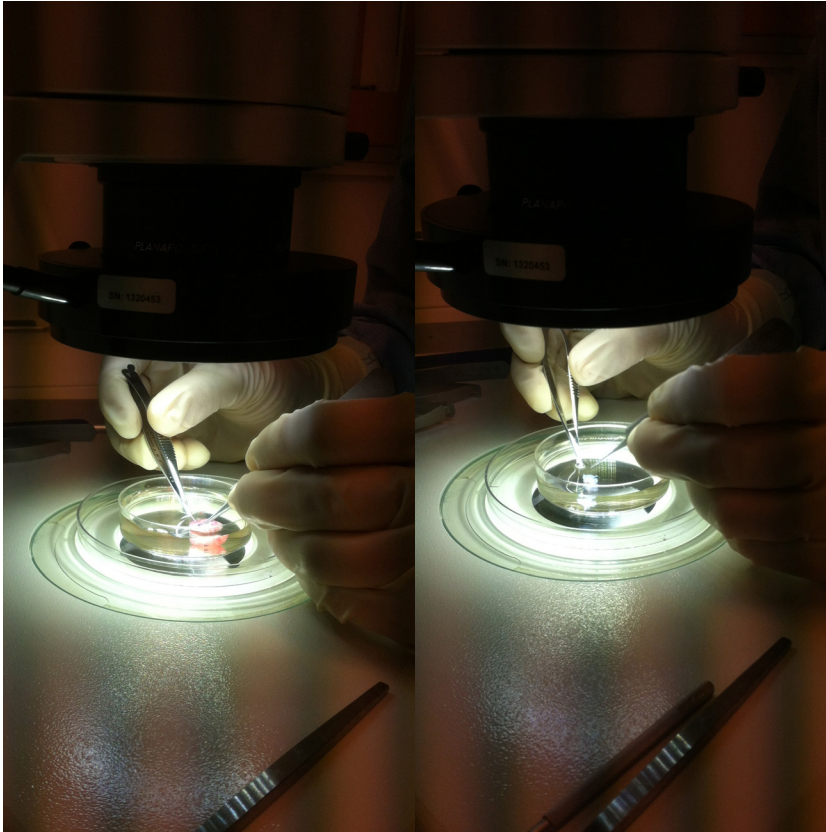


Figure 6: Disassembling and dissecting is done in focus – optically as well as mentally. The features connecting the embryo to its human origin are now being removed.

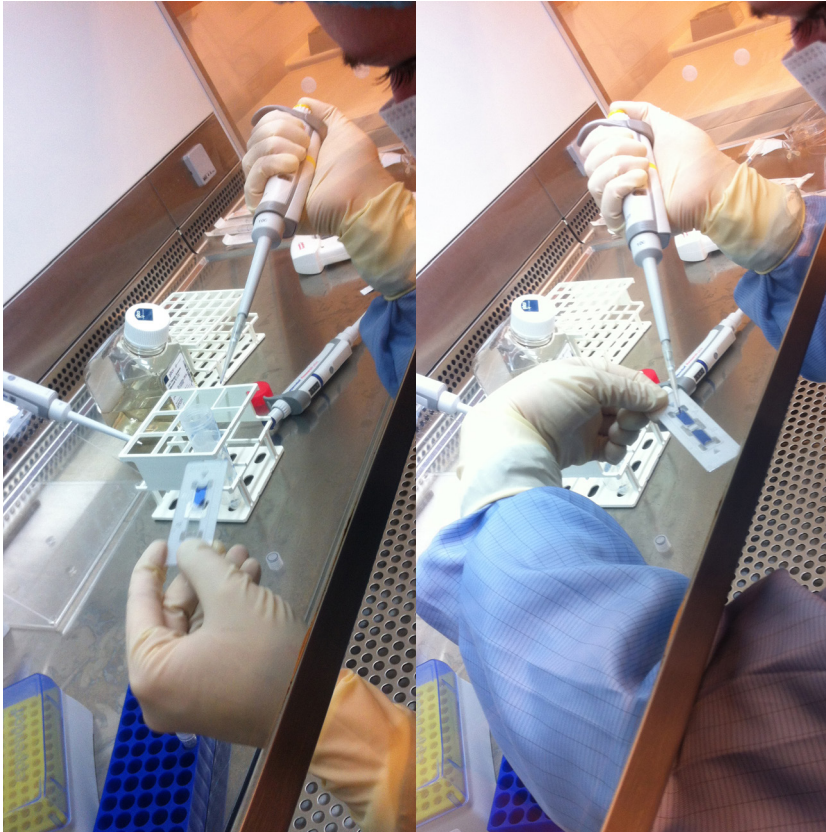


Figure 7: Sacrifice of cells. As scarce as they are, a toxic dye must be applied to some cells to test their viability. These must then be discarded.



Figure 8: The Countess is a biotechnical oracle predicting that there are enough viable cells to transplant.

## Preparing cell suspension

The dissected foetal cell tissue has been put in solution in a small tube and heated in the incubator for twenty minutes. The solution is changed and the tissue is rinsed now and then. The regular rinsing is done to prevent the cells from clumping together. After this step, the tissue is to be washed and dissociated just before transplantation. Emma will carefully follow each step described in a protocol spread out on a counter in the lab, and see too it that she checks each step off the protocol after carrying it out.

She is off to fetch an icebox for the cell suspension to be cooled in, during transportation to the animal laboratory for transplantation to rats. When she comes back, Emma starts dissociating the tissue in an enzyme solution that also facilitates DNA separation and prevents it from clumping. Emma then stops the dissociation of the cells, pipettes the liquid and adds the DNA separating solution, which she gradually changes. This is a washing process that also dilutes the enzyme. Emma tells me that they do all these steps manually to avoid centrifuging. The foetal tissue is considered far too sensitive for such treatment.<sup>30</sup> Because of their sensitivity, another medium, a kind of nutrient solution, is added to the cells in order to create a gentler environment for them. “This provides them [the cells] with what they need,” says Emma, while struggling with getting the right volume of solution.

She pulls out her old glass pipette in order, hopefully, to get a better cell survival count than they previously have had in the trial. Emma suspects that the new plastic pipettes are to blame for bad results in cell survival. This is an attempt to generate better results. The pipette change is made in this particular step because now the cells in *themselves* (and not just the surrounding liquid) are to be pipetted in order to separate them even more. With this new standardized protocol that has to be followed by all the sites participating in the trial, the tissue first also needs to be plucked out of the container in *pieces*, before it is dissociated. This is because it cannot be mixed with tissue from other embryos. Before they entered the trial, they could mix different foetal tissue in one single cell preparation when transplanting to

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<sup>30</sup> Later in the trial centrifugation is added to the protocol since it is concluded that it did not affect the cells negatively.

rats. Now they need to be stricter in keeping them apart, in order to prepare for the trials in humans. The origins of the tissue need to be completely traceable. Therefore, Emma now also needs to check the tissue for contagious disease, such as different sexually transmitted diseases and others, by taking samples and sending them in tagged tubes to another laboratory.

Emma pipettes the cells five times per two different pipettes, before they go back in the same tube and solution. While she is doing this, we talk about how medical abortions may affect the cell viability negatively. Taking a pill is cheaper than surgery and may be done in the home of the aborting woman. However, it may cause the embryo to die before it is evacuated from the uterus, which is not optimal for using the cells for transplantation. The cell survival should be about 80% or more in the material that is used as transplants. While manually (and not by centrifuge as is otherwise usual) dissociating the tissue, a piece of it is suddenly stuck in the narrowest part of the pipette. When finally coming loose, it is shot up in the container of the pipette, and stuck to its wall. This is not good. Emma tries to get it down in the neck of the pipette again, by extracting more liquid into it, but it is stuck. Now there is even less tissue to dissociate and transplant. Emma underscores how important it is that this does not happen when they go into the actual trial with humans. She tells me it is a drawback of using the glass pipettes, but that they seem to give positive outcomes in the form of better cell survival.<sup>31</sup> She adds Trypan blue to the prep sample and puts some droplets of the sample on a glass slide and checks in the microscope. Today, there are no blue spots, which means that all the cells are alive and all tissue can be used.

She puts the tube, containing four microlitres of finished and controlled prep, on ice in the Styrofoam ice box she fetched earlier and carries it down to James, who awaits her in the transplantation laboratory of the animal house. We meet up with James in the staircase hallway. The animal house and laboratory is located behind a totally anonymous door. Emma hands the box to James, who takes me through this door, and shows me the ladies'

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<sup>31</sup> It was later discovered that the bad results and deviations were due to differences in protocols over participating sites, e.g.; the different research centres used different methods for counting surviving cells in the preparations as well as how well the transplants made contact in the transplanted host rat brain – what is called innervation.

dressing room. I am instructed to change into green scrubs, a hairnet and a pair of green slippers.<sup>32</sup> We walk to the so-called stereotactic laboratory,<sup>33</sup> in which two male researchers are already working on anaesthetized rats in their benches. As a contrast to the serene but serious atmosphere of the cell lab, this room is filled with the background noise of British radio delivering pop music hits in between the commercials and the comments of the host. The room also has a faint smell of urine and litter, and holds three working benches with small stereotactic frames and air flow hoods. It lies in relative darkness, except for the small but strong spotlights above the operation tables, focusing both light and the concentration of the researcher on the rat to be operated on. There are plastic cages containing one or two rats everywhere. Inside them are also wooden chips, water, food and nesting material. The rats are female albinos, because “They are more sociable and rather live together,” says James.

He puts on gloves, and shows me an anaesthetized rat, which he will be working on today. He talks tenderly of the rats, and comments on how cute the unconscious one in front of us is. She has already been shaven on top of her head. James now puts her in the miniature stereotactic frame. While doing that, she urinates on his hand. James makes nothing of it, but proceeds by showing me how we know that she is properly anaesthetized by poking her wide-open eye. James also pinches the thin skin between her thumb and toe on one of her paws. There is no reaction to either of these actions.

### Transplanting the cells

James tells me that the rats are prepared beforehand through surgery and a locally injected substance which kills the dopamine production in their brains. Two weeks have gone by and they have now developed symptoms of Parkinsonism. James makes an incision in the scalp of the rat, and weights

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32 I have also been informed beforehand that taking photographs in any parts of the animal house or lab is strictly forbidden, due to risks of attacks from e.g. representatives of the animal rights movement.

33 Stereotactic surgery is a minimally invasive kind of surgery, in which a three-dimensional coordinate system is used for locating the sites of action in the body when planning and carrying out an operation.

the skin down. He wipes the blood off with cotton buds. The coordinates for the target sites of the transplant are measured with the help of the bregma (the fontanelle in the adult). James makes the calculation based on a standard for the species instead of the individual measurements, which surgery on a human being would have required. He marks spots on the skull with a pencil, before moving on to drill the spots with a dental drill. Two holes are drilled on one side of the head. A thin layer of remaining bone is removed with tweezers, in order not to damage the brain with the drill.

James absorbs the cooled cell suspension with the injection needle, by the amount needed for one injection at a time, in order to get the volume as correct as possible. He sets a timer for the injection, to make it slow enough. It is important that the solution is 'absorbed' into the brain at the right pace. He injects a small volume every 15th second for 2.5 minutes. In total James makes injections at four sites: two horizontally, and two vertically beneath them. He washes the needle in between the two separate injection holes.

He comments on the drawbacks of the needle he uses for injecting the foetal cells. When working with human embryonic stem cells, he uses a glass pipette for the injections, which enables him to actually *see* the suspension going into the brain of the rat. Working with foetal cells, he has to use an opaque metal cannula, which obscures the event. He wants to know for sure that the right volume of liquid has been injected. James has already checked for 'left-over' cells post injection in the cannula numerous times, by rinsing the needle and making a cell count on that liquid just to be sure. Nothing indicates that more cells are left post injection in the cannula compared to the glass pipette, but the fact that he cannot witness the injection itself still makes him a bit anxious of the actual result.

While we wait in between the injections, James tells me that every individual rat has a medical record and that a veterinarian visits the animal house every day to check on the rats. The veterinarian is also available for emergencies at all hours. We go on to talk about the difference in handling foetal cells compared to embryonic stem cells. James explains that foetal cells are so much more sensitive because they have already started to develop into neurons and are thereby much more dependent on their surroundings. Therefore, it is not easy to know if they are in the right state



of development. They are so sensitive that they risk dying from being exposed to the most common biomarker<sup>34</sup> available. Best is to let the tissue be as 'raw' or unprocessed as possible. Even the enzyme protecting from DNA tangles risks ruining the cells, which means that the researchers have to make do with a relatively crude cell suspension.

James finishes the injections in the rat, and starts sewing the incision on top of her head using absorbable suture thread. He removes her from the operating bench and she receives an antidote for the anaesthesia that also contains analgesics, better known as painkillers. James touches up the marking on her tail; number 25, before he puts her into the cage with her cage mate, number 28. Rat number 25 will also receive an immunosuppressant as a daily injection for the rest of her life. The drug used will be Cyclosporin, which is also used in transplanted humans. It will help cell survival in the transplant. Without it, all transplanted cells would die within a week. The rat would, however, feel just as good without the drug. The cage is now put on a heating plate, since the body gets cold from the anaesthetization.

### Simulating Parkinson and evaluating the transplant

James shows me the behavioural laboratory where they perform e.g. the rotation tests before and after the transplantation. Two weeks after the researchers have induced Parkinsonian symptoms in the rats by an operation injecting a toxin destroying the dopamine production in their brains, the rats are given amphetamines in this lab. The drug makes them hyperactive, and you can check how they use their paws when moving around. The rats spend 45 minutes in plastic spheres with a wire around their bodies, measuring movement and feeding the data to a computer with analytic software. A successful cell transplantation should generate a rat using only the paw opposite to where the brain laceration has been made, making them move only in one direction. Two weeks after the transplantation of the foetal cells, the same tests are performed again. Then the symptoms should be reversed or significantly less.

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<sup>34</sup> In cell biology, a biomarker is an added molecule that allows the detection and isolation of a certain cell type or protein.

## Sacrificing the animal

Finally, James shows me the euthanization unit. Here, the rats are killed by decapitation. The bodies of the animals are washed of all blood by having their chest opened and a needle pumping water through their hearts and their bloodstream. The same mechanism also pumps formalin into the animal, which works as an embalming fluid. This way, the researchers can save and make use of the body parts of the animal relevant for further research. In this case, it is of course the brains. The procedure is called perfusion, but the expression is often used to refer to the killing of the animal itself. Sometimes, the killing is instead described as sacrificing the animal.

When we enter the room, a female researcher is perfusing a small mouse. Its body and paws twitch as the water runs through its bloodstream, making it behave like a puppet. A male researcher has just decapitated a rat, whose body lay still twitching in the waste bin. He cuts the skull open and plucks the brain out, which he then puts in a small plastic container with formalin. It will sit there until it is sliced, scanned and histologically<sup>35</sup> analysed. I am invited by James to come and look at this procedure later.

We walk down to a room filled with binders. Here the protocols of the ethical permit are to be filled in for each rat handled every day. The health of the animal and all procedures done to it, and the medicines it had administered, must be recorded. All researchers must do this, in a binder that is designated to the specific research group to which they belong. The Board of Agriculture can make unannounced visits at any time to check on this. Should there be any issues, there will be consequences for the researcher as well as for the entire research group, leading to delays, or worst-case scenario, to a shutdown of the trial.

## Brain slicing

Entering the histology room, James starts with a theoretical tour in literature and documents, in order for me to get a pedagogical introduction

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<sup>35</sup> Histology is the anatomical study of the microscopic structure of animal and plant tissues.

to what will take place in here today. He shows me a binder with a series of pictures showing all possible slices from a rat brain from different perspectives. He then shows me information sheets on different biomarkers used to dye specific proteins, in order to trace them. These will help the researchers visualize e.g. the growth of neurons post transplantation.

The room where the slicing will take place has an open-plan office design, with long, shared working benches with cupboards above, dividing the room. Here and there, specific communal workstations with certain tools or machines are placed. This is the only room that I have visited in the process so far that has natural lighting from a wall of windows.

The brain that we will be slicing here today is already embalmed and swimming in a nutrient solution with sugar. James will now prepare crushed dry ice for freezing the brain, so that the slices will be as straight and smooth as possible. He puts the ice in a bag and crushes it with a wooden club. He then fixates the brain onto the platform of the slicing machine with polyvinyl gel, after cutting the cerebellum (Latin for 'little brain') off. When James puts dry ice around the platform and covers the brain in it, both the brain and the gel freeze straight through. He starts the slicing with a machine very similar to the ones used for slicing ham or other sandwich meat in a deli. However, the slices here are 0.35 micromillimetres thin and the meat cut up is rat brain (see figures 9 and 10). A transparent plastic box with small circular containers for putting the slices of the brain in has been prepared with an anti-freezing agent in advance. The agent will prevent the slices from crystallizing water into the cells when put in a freezer. James marks the lids with the number of containers to be used, which today is numbers 1-6. He will collect each sixth slice of brain in order to have a sample of each part of the relevant brain region. He uses a thin brush to put the first slice in the container marked 1; the second slice in number 2, and so on. He keeps doing this, until he has covered the relevant brain region.

The next step in the process is to pour all slices from one container into a petri dish with saline and sort them in order of size. Now the tagging of the relevant protein and cell type is done with a biomarker, in this case a dyed antibody. When finished with all steps, James puts the slices back into the respective containers and puts all the lids on. He wraps the box in plastic film to secure it from leaking when before he puts it in the freezer.



Figure 9: Slicing brain, making data. Evaluating the transplants in rats is a very important part of the process, as it forms the basis of the decision to go ahead with transplantation to human trial subjects.



Figure 10: As the embryo is a centrally staged medical object in the laboratory, so is the rat brain in the histology room.

## Innervation count

We move on to the room in which the innervation count is being done with the help of a microscope. This room is rather small and without windows. It has a couple of working benches and cupboards, as well as a couple of microscopes. In here you must work in relative darkness, in order to be able to focus in on what's on the slide in the microscope. James shows a large and heavy book called *The Rat Brain Atlas in Stereotactic Coordinates*, which they use to navigate the brain in transplantation and which presents the average anatomy of the rat brain. The brain slices we will be looking at today have already before been sliced, frozen and put onto glass slides. He shows me some different slides, before putting one of them under the microscope (see figures 11 and 12. It has two sets of binoculars, so that we can look together at a slide. He explains the structure that we are looking at, but also where the cells have died after they stopped the dopamine production with a toxin in the rat, prior to the transplantation. Here, the structure is completely white. We move on to look at the transplants. The foetal cells that have grown into the brain are visible as a brown mass. The individual cells have a brown outline, while the cell nucleus is still white. Some of them have already started to grow axons (a nerve thread), which is a sign of innervation. In order to analyse and measure cell survival, James makes a reading of the slides in a microscope scanning them directly into a computer. A picture of a complete rat brain is created. For analysis, he uses Photoshop and different marking tools to count cell nuclei in each slice according to a coordinate system.

This is where the laboratory work directly related to the making of cell suspension, ends. This is also the end of the ethnography for the purposes of this thesis. Now, a more theoretical and conceptual analytical process starts in the trial. Data will be analysed, meetings held addressing the data, strategies for progress discussed and articles on the results will be written.

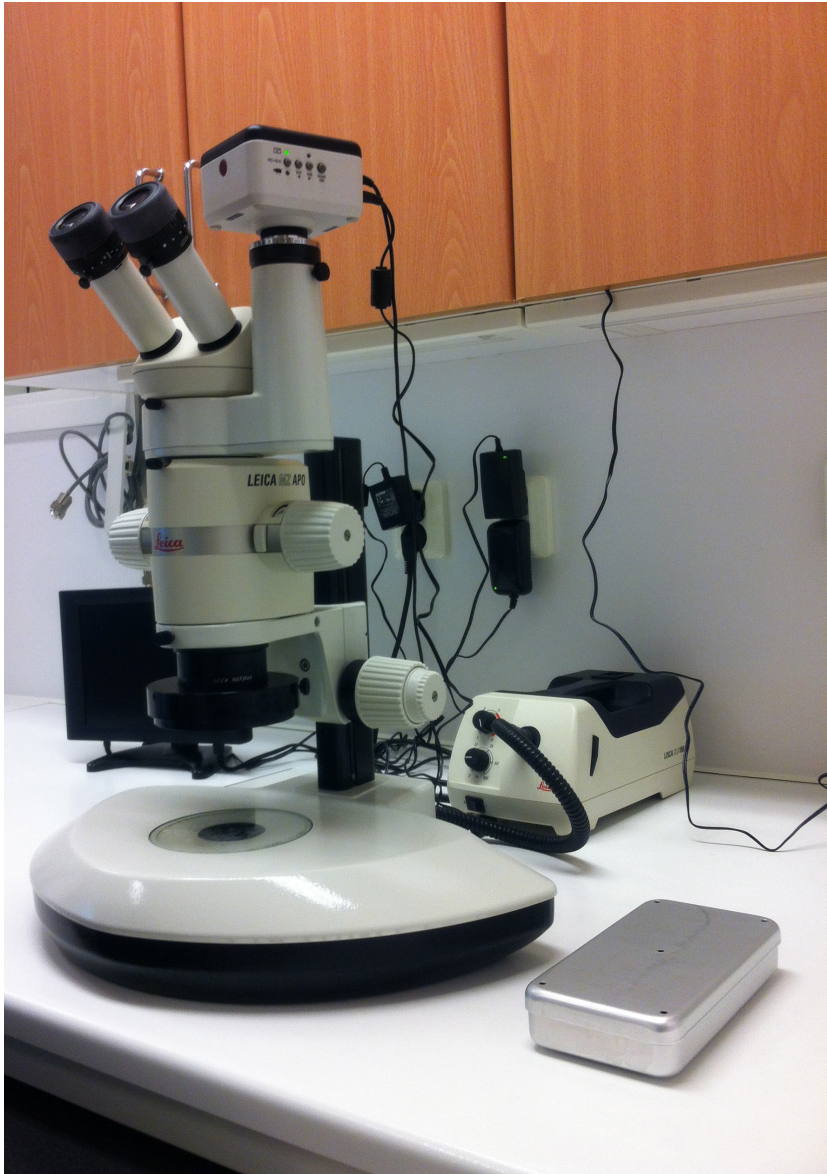


Figure 11: The microscope is an important tool in the making of cell suspension. When counting living cells manually, as well as when evaluating innervation of transplants in sliced rat brains.



Figure 12: Brain in suspense. Frozen in time to be made into data. The dark areas in the brain slices mark the transplants.

## Connections and communications of the cell

In the above, some key events in and of the laboratories – from embryo collection to innervation count in the rat brain – have been described. As an account, it is limited in time as well as in space, and makes the events come off as isolated. However, surrounding these practices is an entire system of large-scale research and trial activities and organization. Besides developing the embryos into a successful treatment, the researchers continuously publish the results from this and other projects in scientific journals and reports.<sup>36</sup> Press releases will find their way into newspapers and may create hope, hype or scare with readers. The researchers attend conferences, reporting on their successes and maybe even their setbacks. Funding is applied for, from private as well as public sector. Emma and James are pursuing careers. The Swedish project leader also needs to have continuous contact with the international project and research leaders of TransEuro, as well as of other large research consortiums and committees. This thesis wishes to visualize and make sense of the production of cell suspension as a bio-object and other cultural products in and of the specific laboratories studied. Still, these locations and the people in them are broadly and tightly connected to a societal context by vast networks of professionals, patients and public.

Tracing these networks further outside the walls of the laboratories is beyond the scope of this thesis. However, moving into some previous research, we will first get acquainted with how some scholars – predominantly within the field of science and technology studies (STS) – have made sense of the relation between the minutiae of the tasks of the laboratories and other knowledge-producing centres, and larger societal context.

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<sup>36</sup> The transplantation branch of the TransEuro trial was recently completed, with a total of 11 transplanted patients, whereof 3 in Sweden. The long-term observational study will continue to follow the transplantees, and the earliest outcome report of the trial may be expected in 2021.



## Previous research

How we view and manage our health and our lives has arguably changed since technical and medical innovation have increasingly gone subatomic and focused on the molecular building blocks of life. These may be entities such as cells, genes and quantum particles. Models of explanation focusing increasingly on the genetics of medicine and psychology, rather than social and environmental factors, have become prevalent. In the highly technological setting in which biomedicine mainly operates, the genome may be said to partly have replaced our soul, and biology can be argued to have become a prominent part of our culture. A ‘genomic metaphysics’ are under development (Mauron, 2002). It is of course only a partial truth that we in our time and in our part of the world use only this molecular gaze of (or from within) the body. The molecularized perception of our bodies can, however, be said to be part of a somewhat older modern mechanistic view of ourselves. Whole and parts are seen as functioning more independently of each other than are they in more holistic balance models of the body (Helman, 2007; Liljefors, Lundin and Wiszmeg, 2012).

As the understanding of the body becomes increasingly molecularized, the circulation of fragmented or assembled hybrids, liminal or cyborgian beings of laboratories increases in the circuits of regenerative medicine, where foetal cell suspension can likewise be found. Many of these have been researched and problematized by e.g. ethnologists, sociologists and anthropologists. They are not only the catalysts of imaginations and sci-fi fantasies, but real-life agential existences. In the form of gene and cell therapies or various assisted reproductive technologies, they may also light a flame of hope – either for cure or alleviation, or for a longed-for child. What these objects may enable and what they symbolize for an ill person, or a person longing to procreate, creates a demand and a market. Like all

desirable things, they may become valuable commodities (Waldby 2002; Waldby and Mitchell 2006 on 'biovalue'). But without technology, skill and labour, there would be no objects to covet. To gain an understanding of this, we need to focus on the bio-object.

## Crossing boundaries and creating knowledge with bio-objects

In this section, examples of research from the ethnologists, sociologists and anthropologists will be given and elaborated on, in relation to the purposes of this thesis and to a market of regenerative value and labour in biomedicine. With a focus on foetal cells, this study may be related to earlier research on medical bio-value produced by entwinement in large networks of monetary and human capital, hopes, needs, demand and biological as well as technical resources. As such, the value may on this scale more accurately be labelled 'biocapital' (Rajan, 2006), as it is used in global transactions of different kinds of currencies. Research on foetal cells for regenerative medical purposes is one example of producing so-called biovalue, even as they are used for a very specialized and limited kind of refinement. The labour of producing the value of the foetal cells is constantly balancing on, and often transgressing, the borders of life and death and of different beings (see e.g. Kaufman and Morgan, 2005). As the embryo is aborted, it is separated from the previously pregnant woman, and – although biographically destined for destruction – its cells are biologically kept alive, in order for them to later reintegrate in another human being or rat. For the social scientist Catherine Waldby, it is precisely the use of cadaverous materials for the revitalization of another still living organism that constitutes biovalue (Waldby 2002; Waldby and Mitchell 2006). And the reproductive properties and products of women – such as wombs, ovaries, eggs, embryos and e.g. the placenta and umbilical cord – have a special place in this reproductive industry (ibid.; Kent, 2008; Pfeffer, 2009). Women's time and effort to bio-physically produce, donate or make available the sought-after biological material is called 'reproductive labour' by Waldby (2010).

Very much in the same way as aborted embryos are not in and of themselves resources waiting to be utilized in Parkinson research – but are

rather transformed into bio-objects of vital capital by policy and by practice – so are the leftover IVF embryos studied by the former historian and feminist scholar Lene Koch. She has been researching stem cell patenting (2009), genetics and genomics (2016), as well as spare embryo donation – the latter together with her colleague the anthropologist Mette Nordahl Svendsen (2008). By following work in an IVF clinic they investigate the conceptual objects of ‘spare’ embryos, and how they are not straightforward biological facts. Complex decision-making processes are required to make them possible objects of exchange between couples in fertility treatment, stem cell researchers and future citizens in need of regenerative medicine.

Another Danish scholar focusing rather specifically on the roles of objects of and with the body in biomedicine is Klaus Høyer. He is a medical ethicist with a past in anthropology, and has written extensively on body – or bodily – parts as medical objects and ways in which they shape practice and policy. He has explored e.g. bio-banking (2008), stem cell patenting (2009), and bone transfer in hip replacement and recycling of prosthetic devices (2013). He elaborates on the concept of ‘object’ (2013), to describe objects that have once been parts of a body and are therefore seen as related to a subject. He argues that this circumstance invokes associations with other distinctions, such as the one between persons and objects, and that this in turn shapes our notions of rights and agency (2013:5). This brings to mind the concept of ‘object’ used in psychoanalysis, to describe something deriving from a subject, but not entirely separate from it (symbolically) and therefore not fully an object (Kristeva, 1982). That is, as something that the body of the subject disposes of, such as discharge, faeces, urine or in the case of my research, a foetus. The concept of object also refers to the reactions of disgust that these products trigger in the person. The process of abjection in psychology is to be understood as a way for the subject to define its borders and achieve personhood. Even if Høyer’s object (2013) comes without the psychoanalytical connotations that the object carries, the concept nonetheless brings us to the aborted foetus, an object rejected from a body, but which in itself is a body.

Pregnancy, the foetus, birth giving and also abortion have in many (if not all) societies been considered liminal (Turner, 1969) in that they all represent the unknown, the transformative, the borderlands of existence

and the margins of life and death. The foetus and the embryo are in many ways considered holy entities, in the medicalized Western world as elsewhere. They are symbols – or icons – of life itself (Morgan, 2009), of innocence, vitality (Rose, 2008) and potentiality (see e.g. Svendsen, 2011; Taussig et al., 2013). As the holiness of the aborted foetus has been compromised by abortion, it is open to the profane world. Labelling the aborted foetus waste excludes it from social and cultural order (Douglas, 1984:39f), but simultaneously enables the availability of the foetal material for research. By making the dead foetus available for use, society has taken control over its border-crossing and ambiguous properties, rendering it less dangerous and less challenging to order. By transforming the foetus into a resource, order is restored and the wasteful process of abortion cancelled. At the same time, the action to utilize (or exploit) the resource has been legitimized with the argument that it is the economical and responsible thing to do in a medical economy with scarce resources of biological tissues. Not using it, then, would in itself be an act of wasting (see Ariss 2003; Waldy 2012). The sociologists Julie Kent and Naomi Pfeffer have researched how the moral judgements and arguments of aborting women for donating foetal tissue to hESC research in the United Kingdom work in much the same manner (2008, 2009). The waste label put on the embryo can be said to release its latent biovalue by making it a commodity of sorts (Waldby 2002; Waldby and Mitchell 2006). By attributing the value of a regenerative and therapeutic vitality for another human being to the foetus, it is re-sanctified and made holy in the name of scientific endeavour (see e.g. Svendsen on Thompson, 2011:422). The concept of the ‘abject’ embryo, as well as the embryo as waste activating pollution behaviour, is further explored in article III with the help of these previous studies.

If the foetus has always been considered ambiguous due to its liminal properties of being both part and whole, the technical developments making foetal monitoring in utero possible (see e.g. Barad, 2003; Williams, 2003) worked to amplify that experience by adding the possibility of subjectivity to the unborn. These are of course not the only developments adding as much uncertainty as they provide answers in modern medicine. The epistemic isolation of e.g. hormones, genes or neurotransmitters as

explanatory causes of disease and as specific targets of intervention poses a challenge to holistic medical models and cosmologies of the body, and possibly to our existential understanding of it. Much new medico-technical innovation tends to make our perception of selves (and others) fragmented and atomized (Liljefors, Lundin and Wiszmege, 2012). By focusing on how dopaminergic foetal cell transplantation is conceptualized differently depending on circumstances for and relation to the procedure – as well as how these conceptualizations are involved in the material production of foetal cell suspension – I, in the articles and chapters, visualize some of the processes that may create cultural uncertainties and alienation, in researchers as well as in patients, relatives and lay-people.

Some modern bio-techniques also enable body parts and bodily products to travel in space, as well as in time, through processes of bio-objectification. As spare or donor eggs are cryopreserved (frozen) until later use, possibly in another woman, life is suspended. In much the same way, it is suspended in the foetal cell suspension followed in this thesis. The vitality of the embryo is harnessed and saved until another time and place – even if temporally much closer than in the case of frozen eggs. In a sense, certain parts or tissues gain a kind of immortality due to this mobility. Genetic material and code can virtually be saved forever. Stem cell lines can be reproduced infinitely. These preconditions produce existential as well as ethical and legal issues that have been addressed in a number of publications by Swedish ethnologists from Lund and elsewhere (see e.g. Lundin and Ideland, 1997; Lundin and Åkesson, 1996, 1999, 2002; Gunnarsson-Payne, 2015).

The possible infinite future of cell lines and genetic material in banks is only part true for whole organ as well as e.g. cell transplantations. The tissue of one individual is transferred into another, so that the recipient's life may be prolonged or enhanced, but only for as long as that individual walks the earth. When she or he perishes, so do – most often – the organs or cells of the other. In a sense, the transplants can therefore be said to experience multiple deaths. While alive, the recipient of organs or tissues may face cultural and psychological unrest, knowing that something 'alien' has been planted inside (Åkesson, 1999; Lundin, 1999, 2001). This 'boundary anxiety' (Brodwin, 2000) is an expression of fear of malign intrusion to our inner selves. The recipients may also, on the other hand,

experience huge gratefulness towards the donor for ‘giving them life back’, and possibly also a sense of not being able to repay the gift and therefore of being in debt (Mauss, 1950).

However, the idea of humanness generally still seems to be an either/or state in our common cultural conception. Most other possible imaginations of mixes are considered monsters of modern as well as ancient fiction. Just like pregnancy, childbirth and also the foetal cell suspension are liminal and challenging to cultural categories, and thus are monsters. But if monsters appear mainly conceptually in tales and stories, they are a reality in biomedicine in the form of bio-objects. There, they offer an interesting gradual scale of humanness and otherness as mind-blowing as the hybrids of histories. The growing numbers of ‘liminal beings’ (Kaufman and Morgan, 2005), such as xenotransplantees (Lundin, 1999, 2000, 2002; Hansson, 2011; Griessler et al., 2012) and transgenic animals (Holmberg & Ideland, 2011) created by medical advances are just some examples of the realization of the Harawayian ‘cyborg’ (1991). They are numerous, and their character and quality differs. One thing that many of them have in common, though, is that they are practically constructed, conceptually and materially. As they are made, they are known. And as they are being known, they may be updated and made differently – thus continuously transgressing new boundaries. The tendency to challenge and cross cultural as well as legal borders makes the bio-objects as hybrids, cyborgs, liminal beings or ‘monsters’ of medical and technical innovations not only interesting but also important areas of research for ethnologists.

## Knowledge in and of the laboratory

Starting with philosophers like Gaston Bachelard (1934), Mihály Polányi (Michael Polanyi) (1946), Thomas Kuhn (1962) and Paul Feyerabend (1975) questioning positivism and rational objectivity, the sociology of scientific knowledge (SSK) has grown broad and large. With the publication of their highly influential *Laboratory Life* in 1979, the sociologists Bruno Latour and Steve Woolgar among others spurred the development of the subsequent field of science and technology studies (STS). Fellow sociologists John Law (see e.g. 1991, 1999), Andrew Pickering – also historian of science and

philosopher (see e.g. 1981, 1995) – as well as Karin Knorr-Cetina (see e.g. 1999) very much contributed to the growing field. Since then, Latour and colleague Michel Callon together developed the now famous actor-network theory (ANT) (see e.g. Latour, 2005), into a methodological approach, stemming from their interest in the different socio-material translations the sciences have to make in knowledge production (see e.g. Callon, 1986; Callon, 1991; Latour, 1987). ANT is now widely applied also in ethnological and ethnographical analyses of diverse scientific, professional and other settings, and has been a great influence for the research style of this thesis too. The ways in which ANT makes possible tracing events, relations, transformations and products of scientific knowledge, whether on a small or a large scale, is highly applicable. It is a tool well adapted for studying the making of bio-objects. Latour really makes visible the extent to which scientific objects are transportable, transferable and transformative, in his now famous account of the ‘paedophile of Boa Vista’. There he shows how soil is sampled, categorized, transported, and referenced as data, used in scientific papers to discuss whether the forest is withdrawing or if it is the savannah that is advancing on the forest (1999). His account illustrates well how the tiniest tasks of science are connected to evidence making, and how these local events connect to a larger society through advanced relational networks. The endeavour undertaken by these researchers in problematizing and contextualizing scientific knowledge – on a philosophical as well as on a more technical and practice-oriented level – has been highly inspiring to my own research interests. The methodological approaches – such as ANT – developed mainly by sociologists of science for studying the socio-material translations in e.g. laboratories and other science-producing sites, have been of great importance to me when choosing field of study as well as my focus and conduct in it. Even if I do not fully embrace the theoretical standpoints of ANT,<sup>37</sup> the methodological aspect of the theory has been an inspiring asset.

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<sup>37</sup> ANT practices a so-called flat ontology, in which human actors and non-human ‘actants’ are granted equal agency. My interpretation is also that the theory rests upon an ontological assumption that the relational assemblages of actors and actants consists of pre-given entities. This assumption is in philosophical opposition to the diffractive approach applied partly in this thesis, rather viewing all experienced phenomena as enacted in the moment.

If the research endeavours referred above were mainly directed to the processes, conditions and consequences of creating evidence and facts per se, there was also an increasingly influential feminist branch of the sociology of science taking a more political interest in the socio-cultural biases and hierarchies in science production and the experiences and conditions they create for the different people involved. The philosopher Helen Longino (see e.g. 1990, 1992, 1997) made great contributions to the discussions on the importance of pluralism and diversity in science. The physicist and science philosopher Evelyn Fox Keller was another influential voice in these debates, who drew on her own experiences as a female researcher in theoretical physics (1992). The contemporary science philosopher Kristina Rolin and the philosopher and archaeologist Alison Wylie (2009) developed the 'standpoint theory' for which philosophers like Donna Haraway and Sandra Harding previously paved the way with the concept of 'situated knowledges' (Haraway, 1988) and the idea of a 'strong objectivity' (Harding, 1995) achieved by considering the experiences of the oppressed and silenced. Conceptualizing how a person's intersectional dimensions of experience form an individual standpoint through which s/he understands the world, the standpoint perspective offers a feminist epistemology. Miranda Fricker (2007) gave us the concept of 'epistemic injustice', as a tool for discussing how unfairness is reproduced by the creation, communication, understanding and interpretation of knowledge itself. These feminist interventions in the conditions of science production and communication have been of great importance to the development of my own understanding and interpretation of science production, as well as of theory of science. Chapter IV of this thesis is an example of how Haraway's concept of 'situated knowledges' (1988) as interpreted by Karen Barad (2007), inspired me to further look into their respective elaborations on fairer knowledge creation from partial perspectives. Applying a 'diffractive approach' (Haraway, 1992; Barad, 2007) in chapter IV, was a way of allowing differences to converge as well as diverge in the meaning and knowledge emerging between me and my participants.

The insights into how science, medical and otherwise, has been able to work oppressively by upholding socio-cultural inequality and



imbalance in the name of objectivity are crucial – to myself when entering this field of investigation as an ethnologist, but also to everyone researching the social, cultural and ethical implications of knowledge production. Many more recent anthropologists and ethnographers who engaged in research in science, technology and often in medicine, contributed to the research field with a feminist perspective on communal meaning and cultural processes. These researchers have of course been particularly influential to my own work, as they combine the medical field of my interest with an epistemological and political perspective close to mine, and an interest in cultural processes. Rayna Rapp, Emily Martin and Marilyn Strathern are just a few – but highly influential – feminist researchers from this discipline in these fields. Strathern groundbreakingly explored the transformative properties of reproductive technologies concerning kinship and the relation of nature to culture (1992). Martin made a famous feminist analysis of the female body as a machine of reproduction (1987), as well as of egg and sperm portrayed in reproductive biology, as highly gendered entities in a romantic drama (1991). Rapp, among other things, wrote an influential piece on the entwinement of genetics and reproduction in e.g. pre-implantation diagnosis (1999). Anne-Marie Mol has also made significant contributions to the field, investigating the ways in which different health care practices are performative and reality producing (2002, 2008).

In a similar manner, some recent Swedish STS scholars have engaged in how medical advances and technologies entangle and co-create the normal as well as the pathological and deviant body, and what kind of medical practices and interventions are thereby sanctioned and what bio-objects are being brought forth. Boel Berner, for example, is an influential professor emerita with a background in history and sociology, who conducted diverse studies on different relations between gender, technology and medicine (1996, 1997). She has e.g. written on the history of blood transfusion (2012). She also published and edited volumes on knowledge practices together with e.g. Corinna Kruse (2013), Ericka Johnson (2010) and Francis Lee (2009). Kruse made an early contribution in using Barad's

agential realism and concept of agential cuts<sup>38</sup> to explain the transformation of samples into data in genetic research (2006). By combining conceptual elements and analytical approaches from the STS field with an ethnological perspective on the concept of culture and a methodological toolbox from the discipline, my study may offer insights to the field on how more symbolic aspects of cultural processes also inform and influence science production.

## Knowledge and objects in ethnology

The basis of science production is the empirical experience. This is also a common point of departure of Ethnology as a discipline, and the basis of the phenomenological perspective. Interestingly enough, much of our mundane experience with things, escape our own awareness. The philosopher Martin Heidegger developed the concept of objects as ‘ready to hand’, to describe the way in which they disappear from our conscious mind when used practically as tools (1927, translated from German to English 1962). They then become extensions of the self. This is to be understood as opposed to the object at distance, as the focus of our gaze and contemplation, as well as of evaluation. The Swedish ethnologist Jonas Frykman develops the idea of automatized acts in his essay “Things as Tools” (2006:76):

It is neither in the user nor in the tool that the cultural pattern resides. It emerges in the meeting, the interface, between the two. Movements and approaches become automatized, internalized. It is not only we that take action and think through the tools. The things also seem to act through us (Author’s translation).

This observation is to a large extent applicable to the cells used in experimental and clinical biomedicine today, and an insight important for

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<sup>38</sup> Agential cuts are, according to Barad, the creative instances of our apparatuses, in the emergence of a phenomenon. It is these cuts that separate things from one another within the phenomenon and make us experience them as separate entities and objects (Barad, 2003; 2007).

developing the bio-object as an analytical concept. In the case of foetal cells, the use and ideas of the cells emerge in the interface between the embryo, the donation, the laboratory, the researchers and the patients. A lot of manual work with the cells is automated and done without a lot of reflection on the part of the researchers. They are objects at hand as well as for scientific and conceptual contemplation. Cells are just as good to think *with* as they are to think *of* (see e.g. Turkle, 2007; Frykman and Gilje, 2003; Heidegger 1962 [1927]). Even though my thesis mainly utilizes other theories in understanding science, they proceed from the phenomenological basis that knowledge is created in being and in doing, in experience and in skill, rather than in pure contemplation. When the cells behave unruly in research and seem to act on their own, the researchers suddenly become aware of the impact of their tools and methods, or the lack thereof. Problems arising in the daily work with the foetal cells in the laboratory enable the invention of new approaches and protocols, as e.g. when changing between pipettes and needles in order to maximize cell count. They also function as a methodological tool enabling contemplation on the borders of life and death, as well as of manufactured and ‘natural’, between the participants in the study and myself as a researcher.

However, the diffractive approach employed in this thesis does not stop at stating that cultural patterns emerge from the meeting between user and tool. Instead, the user(s) as well as the tool(s) are seen as part of the pattern, or phenomenon, rather than being the origin or cause of it. Being as well as doing are constitutive for and within the phenomena we experience. Foetal cells are expressed and interpreted differently depending on the modes of being of the cells, and the different modes of doing of the professionals and of others handling and relating to them. The different modes of being of the cells enable the actors’ different agency or modes of action and knowing. The different modes of knowing and doing of the actors in return give the cells different modes of being. Briefly, this means that the cells actually are different phenomena for researchers (article II and III, chapter IV) than they are for patients, relatives or for non-afflicted people (chapter I). Also, these different categories of people have different means of making the cells emerge differently socially and/or materially. But as these constructed categories often intersect in reality, the knowledge

created by them together cannot easily be either choreographed or separated. This thesis is however an attempt to outline some differences and similarities.

The ethnologist Eddy Nehls, who has written extensively on knowledge and on learning in different contexts (see e.g. Johansson, Lassbo and Nehls, 2013), wrote in his private blog considering the topic of ‘work integrated learning’ (WIL) – an approach to learning combining classroom learning with practical work experience – on October 23, 2012, that:

Work integrated learning is *what* emerges between the actors as a result of the *interaction* between them. You cannot know in advance what this ‘something’ might be. Co-production, or reciprocal becoming, are crucial keywords. And it is just as important that all parties understand that the result, what comes out of the process, by definition cannot be decided beforehand. WIL is an open, non-linear process of reciprocal becoming and it can subsequently not be managed by instruction.<sup>39</sup>

Even if directed towards a specific mode of learning and teaching, I argue that this line of reasoning would beneficially be applicable to a wider array of knowledge creation. Ironically enough, the instruction-based knowledge production that Nehls criticizes is the exact aim and also precondition of evidence-based science. Still, as shown by article II and chapters III and IV, not all outcomes or products of such processes are necessarily standardizable themselves. However, Nehls’ argument is central to the diffractive approach explored to some extent in this thesis. It describes well the cultural knowledge creation around the foetal cell suspension, which I have used to illustrate this point. Scientific practices in themselves, in a contradictory manner, visualize the inseparable, fused and entangled character of reality precisely due to their separating, formalizing and standardizing endeavours.

Skill and knowledge is, as will be shown below, a common research object for ethnologists. They are in a sense natural pathways into understanding enculturation as well as cultural transformation in groups over

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<sup>39</sup> Source: <http://flyktlinjer.blogspot.com/2012/10/en-vision-om-arbesintegrerat-larande.html> (Link retrieved on October 31, 2018 and translated from Swedish)

time, as well as the simultaneous transfer or transformation of norms and values within and between communities. Skill and knowledge have been addressed, conceptualized and problematized in many different ways, due to the vast number of fields the discipline spans over. The common interest in diverse everyday and cultural expressions is however in itself a way of taking seriously the many transformations, accounts and practices of knowledge existing and forming. For my purposes, however, I will address some scholars who in some way directly and actively discuss knowledge production and explanation in research or in professional settings.

Eva Fägerborg (1996) explored how profession as a social experience contributes to foundational ideas about reality, and found that tacit knowledge (Polányi, 1958; 1966) was seen both as an instrument and as an asset or capital to be invested. With her thesis, she researched the entwinement of practical know-how and cognitive thinking in manual work in a Swedish industrial workshop in the early 1990s. This was a time characterized by financial crisis as well as an increased capitalist drive to make large profit, established during the 1980s. The tacit – unspoken and implicit – knowledge, was able to work as a protective zone against alienation for the collective of workers, and hence helped create meaning and value for their efforts. Even if far from my field of research, Fägerborg’s interest in how practical labour and abstract cognition cooperate in daily work as well as in reality experience and construction is very similar to my own. In Karin Gustavsson’s dissertation (2014) it is the knowledge practices of ethnologists from the past, in the form of ‘expeditions’, which are scrutinized. The scare of the presumed disappearance of the peasantry was at its height in the early years of the twentieth century, and restless documentation of buildings and artefacts was undertaken. Gustavsson describes and analyses how new technologies enabled new knowledge, but also posed new challenges to the (almost exclusively) young male students engaging practically in this endeavour, as well as to the discipline of ethnology in itself. Technical innovations sped up some aspects of knowledge creation, while others were made significantly slower. Gustavsson’s general interest in science theory and her firm grasp of the material aspects of the expedition work resemble my own points of departure. Her application of ANT in understanding

how the documentation of the ethnologists was translated into knowledge in archives has been inspirational for article II and chapter IV.

Elias Mellander transfers the issues of the work practice of ethnologists to the contemporary labour market in his dissertation (2018). Rather than focusing on specific tasks per se, he targets the ways in which the skills and the knowledge of ethnologists can be put into practice today, and by what rationales ethnology graduates orient themselves when navigating a knowledge society in change, and how they align with the discipline when working outside the university. This is connected to the growth of the so-called knowledge society, which really was a source of discussion and debate in its early days, in the twentieth century. Virtually every job would soon require a higher education, as well as flexibility and adaptational skills in their employees, – conditions which ethnologists and other humanities scholars fresh from the graduation ceremonies very much can relate to today. However, the instrumental view of knowledge that such labour market politics have was not welcomed without friction in the humanities, which traditionally advocate education as an end in itself. The discipline of ethnology answered with part adaptation, part resistance. One contribution to the debate of knowledge as capital and instrument was materialized in an edited volume (Idvall and Schoug (Eds.), 2003) in which ethnologists from different departments discussed politically broader topics such as the competence industry (Salomonsson, 2003), the so-called crisis of the humanities (Schoug, 2003) and the concept of human capital (Gustafsson, 2003), as well as more specific areas of expertise knowledge, such as the speed of knowledge and upgrading in the IT business (Willim, 2003) or the strategic role of information in xenotransplantation development (Idvall, 2003).

From the vision of the knowledge society sprang the idea of the importance of multidisciplinary research environments. Helena Petterson wrote her dissertation on the multidisciplinary research community *Tools for Creativity* in Umeå, acting within the field of ICT, information, communication and technology (2007). She investigated the relationship between humans and technology and the employees' understanding of this relationship, as well as how the idea of research and the role of the researcher are defined and negotiated in multidisciplinary collaboration. Research in

itself, like the role of the researcher, she argues, is a boundary object for the working community. This very much resembles the ways in which my participants and myself talked about research – seeking affinities as well as delineating differences. The foetal cells in themselves also functioned as a boundary object, not only in my analysis but also between us in our conversations. The cells were similar enough for us to be able to communicate, but different enough to enable diverse understandings as well as practices (chapter IV).

Conditions and consequences of experiential and expectational differences as well as similarities specifically in biomedical research have been observed and elaborated on by other ethnologists. Both Susanne Lundin and Kristofer Hansson have explored knowledge processes in the multidisciplinary settings of neuroscience. Lundin (2012) e.g. explores the inevitable entwinement of private and professional knowledge, and of everyday practice and professional ethics in biomedical research. Hansson (2017) makes a similar observation, but concerning the discrepancy in experience and knowledge between researcher and patient, and how the researchers handle this difference in practice in their daily work.

Against this background of the emergent ‘knowledge society’, functions and opportunities of ethnologists and ethnographers may be discussed, as relations within and between disciplines and with different lines of businesses change (Ekström & Sörlin, 2012). An important contribution of this thesis – inspired by the discussions of the role of humanities and of ethnology in the studies above – may be how a diffractive approach can offer tools to discuss knowledge production in a cross- or multidisciplinary way, as well as how an awareness of our common boundary objects may do so. This issue will be revisited in the final paragraph of this thesis, called “Contribution”.





## The articles

This chapter addresses some boundary-bending and some cultural products enabled by the foetal cell suspension manufacture into a bio-object. The individual articles and chapters of the thesis will now be presented. The order chosen for the presentation of the chapters and articles is meant to give the reader some guidance in the argument of the thesis. The first two texts appear chronologically, but the last two have shifted order. This is because chapter IV addresses a methodological approach and a framework for understanding knowledge production in ethnographic fieldwork more generally, which arguably extends and is applicable outside the scope of this particular study. The methodological contribution and epistemological discussion of this chapter is presumably also best understood if read last, as it in a sense summarizes the experience and ethical deliberations in and of fieldwork and analysis.

### 1. Medical need, ethical scepticism: Clashing views on the use of foetuses in Parkinson's disease research

Wiszmeg, Andréa 2012:  
in Liljefors, Max Lundin, Susanne and Wiszmeg, Andréa (eds.)  
*The atomized body: The cultural life of stem cells, genes and  
neurons*. Lund: Nordic Academic Press. P.: 65-82.

The focus of the dissertation is primarily on the laboratory and the events taking place there. Still, some material has nonetheless been collected outside the laboratories, prior to my visits to them. The practice of the laboratory may seem like science fiction for the uninitiated, and is not

something the public usually has concrete experience of. Discussing developments in biomedical technologies in focus group interviews helps visualize how individuals with different expectations and experiences relate to different ethical issues raised by these techniques.

The chapter demonstrates how foetal cell therapy as a concept enacts different expectations, emotional responses and ethical deliberations in patients, relatives, researchers and in non-affected persons. It also shows that if these categories intersect in one individual, so does the meaning provided to the foetal cells, and the ethical negotiations become more nuanced. The focus group interviews asked the participants questions on the themes of *Opinions and knowledge about the use of foetal neural cells*, *Possible participation in a sham-controlled trial*, if they were patients, or *Attitudes towards sham surgery ostensibly using this therapy* if they were relatives or non-affected, as well as *Views on differences in safety and ethics in foetal neural cells versus stem cells*.

The chapter provides a discussion of the generalizability of Ulrich Beck's concept of 'ethical reflexivity' (1992) as a general key component of contemporary modernity.<sup>40</sup> The focus group conversations demonstrate that the occurrence of this ethical reflexivity is highly dependent upon the individual's role and position in relation to Parkinson's disease. The patients and relatives of the focus groups – who were in some way closely affected by the disease and the effects and futures it presents – did not at all to the same extent display this kind of ethical reflexivity. Rather, they showed a kind of harsh pragmatism, in which there was not much room for reflective detours on whether e.g. the use of aborted foetal material could be considered ethically problematic or not (see e.g. Lundin, 1999). The utilitarian perspective that, if abortion is already decided on, there is no harm in using the material – was often applied. The embryo<sup>41</sup> may as well

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<sup>40</sup> The reason for discussing Ulrich Beck (1992) in this chapter is that it is meant to be in discourse with Lundin's chapter "Moral Accounting", in the same volume. Lundin there utilizes Beck's concept of 'ethical reflexivity' and discusses modernity and ambiguity in relation how researchers in regenerative medicine reflect on the ethical dimensions of their work. I wanted to offer a slightly different perspective with other, yet related, empirical material.

<sup>41</sup> In this chapter, the definition foetus is used instead of embryo. It still refers to the material used in the TransEuro trial, which are by gestational age defined as embryos. However, as the script we employed in conducting the focus groups interview defined it as foetuses, this definition unfortunately remained in my chapter.

be used for benevolent purposes, such as possibly curing an ill person or searching for a cure, it was argued. The only way of not wasting the embryo entirely is by saving it and making it a resource for research and therapy instead (Lakoff and Johnson, 1999).<sup>42</sup> Beck's ethical reflexivity is to be understood as an answer of the modern (hu)man to a presumed 'risk-society'. The kind of risk that Beck discusses and proceeds from is as a vague and unpredictable threat that society encourages us to acknowledge. However, the patients afflicted with Parkinson's disease are faced with a very real and concrete threat. Therefore, I argue, they cannot afford the relative luxury of ethical reflexivity, as understood and explained by Beck.

Still, the use of aborted embryos in research and in medicine does evoke some unease, albeit mainly stated explicitly in the non-affected group of participants. I elaborate on how this unease is an expression of 'gut-feeling ethics' (cf. Lundin 2004:189, 2012:25 – in the same volume as my chapter), and how it is in turn connected to boundaries of humanness (Haraway, 1991; 2008). The immediate responses of unease, often correlated with discussions about which beings can be labelled human when, and which cannot. The arbitrary definition of when an embryo has reached the developmental stage of a foetus functions as an important guide, not only legally, but as a point of reference in ethical and cultural reflections too.

## 2. Cells in suspense: Unboxing the negotiations of a large-scale cell transplantation trial

Wiszmeg, Andréa 2016:  
in *Ethnologia Scandinavica*, Vol. 46(2016). P.:104-123.

To reach a cultural understanding of how the laboratories achieve a homogenous and mobile cell suspension, it is central to investigate how the different actors in the trial – human as well as others – are choreographed (Thompson, 2005) in time in space. It is in this choreography that scientific

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<sup>42</sup> This is further elaborated on, using the concept of waste, in article III.

and ethical consequences are produced by the negotiations and compromises needed. Focusing on this, it is possible to understand social and cultural processes in the laboratory.

The article draws the outline of some basic contexts and conditions of the trial and shows how temporality and delay play crucial roles. I proceed from insights gained when waiting for my individual fieldwork to be able to start. Practical tasks, administration and logistics within the TransEuro trial often seemed to contain dimensions of knowledge creation as well as issues of an ethical character. These dimensions were however often obscured by the practicalities of the tasks and their experienced mundanity. Assumptions were made about the nature and the state of entities and actors involved – assumptions that were not only *descriptive*, but rather *prescriptive*. Such prescriptive assumptions often showed in the attempts to homogenize protocols and ethical permits. As the presumed character and behaviour of foetal cells and of foetal material, as well as of e.g. performance of equipment, were written into documents, they were also etched into the reality of the trial almost metaphysically. Therefore, the consequences of such assumptions risks being hidden, it is argued in the article. In order to reach into the constituents, construction and consequences of these assumptions, the study focuses primarily on internal and external documents, guidelines, ethical permits and procedure descriptions. Information gathered in the preparation for fieldwork via meetings, e-mails and phone calls, as well as from the nine planning group meetings attended, were also used to construct the empirical material for this article. These sources provided me with the complex and nuanced kind of material needed for understanding the trajectory of the trial, as well as how different aspects of delay and development affected the involved actors and objects differently.

The aim of the article is to explore the dynamics of how these assumptions are created and utilized in practice, with regard to how it affects what is considered ethical issues and what is not, and how this negotiation is handled. Much of the procedures this entail are made mundane and taken for granted in the day-to-day work of the project, and the implications that this has for chances of ethical reflexivity need to be investigated. By looking into the negotiation processes that had to take place within the trial, in order for it to pick up pace when faced with large and problematic

delays, I examine how these delays were connected to what could be defined as ethically sensitive issues. The focus therefore is on what – according to staff – caused the major delays. With this focus, temporality becomes an important factor in the homogenization and reproducibility of science. The changes and negotiations examined were mainly undertaken to meet the aims and standards of evidence-based science, but have implications for research practice and ethical reflection and perhaps even conduct. Bruno Latour's concept of 'black-boxing' (1999:183) is applied in order to explain the process by which knowledge and concepts are closed off and made consensual. The different and strenuous efforts needed to open what has once been black-boxed – for example non-functioning prescriptive assumptions – is explored and understood through the concept of 'un-boxing'. The concept helps to show the difficulty of opening closed boxes of knowledge, and explains why this must be avoided at all costs.

The delays experienced in the trial therefore need to be seen not only as a consequence, but as a kind of strategy for reaching the standards of evidence-based science. The different actors need to be choreographed in a specific manner, in order to achieve a homogenous and mobile cell suspension. As foetal cells carry with them some uncertainty – biological as well as ethical-, this is somewhat difficult. To take the time needed to create an unbroken chain of procedure over time and space seems to be crucial to avoid entering practical as well as philosophical and ethical deliberations later on in the process.

### 3. Transforming trash to treasure: Cultural ambiguity in foetal cell research

Wismeg, Andréa; Lundin, Susanne; Mäkitalo, Åsa;  
Widner, Håkan (manuscript)

Accounting for the view of the public, as well as patients and relatives considering ethics in cell transplantation research, does not safeguard from dilemmas having to be handled in practice. Nor does organizing the research and the trial in a certain way. Ethical issues are unavoidably part of the daily practical work, and must therefore be managed there too. It is

not possible to anticipate and plan everything beforehand, as the people working in these environments are as changing and changeable as the foetal tissue they handle. Therefore, focusing on the individuals dealing practically with the tissue as well as the ethical issues it presents, on a daily basis, is of the essence.

This article examines different discursive strategies used by researchers in the laboratory to handle ethical dilemmas emotionally and cognitively, in a large-scale foetal cell transplantation trial in Parkinson's disease research. It responds to the question of how such dilemmas are produced in tandem with the foetal cell suspension, in everyday professional practice in the trial. It addresses how the researchers express and handle these dilemmas in daily practice, by analysing interviews with two researchers targeting the topic. We do this by letting the two researchers problematize how expressions and concepts in language are related to mundane tasks as well as to the goals of the trial. The interviews were analysed in the light of previous observations in laboratories, as well as close readings of instructive documents, using the anthropologist Mary Douglas's concept of pollution behaviour (1966) to explain and make sense of the results.

The findings reveal how the manual and linguistic labour performed by the researchers in the trial work to transform the foetal material from trash to treasure, practically as well as culturally. The transformation process contains different aspects, of which the following were observed in the interview material: the foetal cell can be considered an object, a subject as well as an abject (Kristeva, 1982; Ariss, 2003) to the researchers handling it. As demonstrated in the analysis, it is the human origin of the cells that makes them abject and activates pollution behaviour in the acts and discourse of the researchers. Rachel Ariss has previously applied Douglas's theories of how dirt can be understood as 'matter out of place' – and how that activates the process of pollution behaviour making it culturally clean again – to discuss the understanding and handling of aborted fetuses. By treating the foetal tissue as waste, it can be made into a resource (2003). Here, the concept of pollution behaviour is applied, to describe how the researchers handle and legitimize their daily processing of foetal tissue, in theory as well as in practice. As the foetus may simultaneously be described as both a holy and a profane liminal object, the researchers inhabit a

liminal position themselves by being in such a close relationship to the aborted embryo and to the cells extracted from them. They are the ones in power to bring the aborted foetus back to an accepted cultural order. The study has therefore examined how the marginal and ambiguous status of the embryo turns the scientists handling foetal cells into liminal characters in modern medicine. Why the use and refinement of a tissue, about which there is practical consensus but cultural ambiguity, deserves further investigation is also addressed.

#### 4. Diffractions of the foetal cell suspension: Scientific knowledge and value in laboratory work

Wiszmeg, Andréa 2017:  
in Hansson, Kristofer and Idvall, Markus (eds.) *Interpreting the brain in society: Cultural reflections on neuroscientific practices*.  
Lund: Arkiv förlag. P.: 73-94.

Proceeding from the accumulated insights gained in fieldwork concerning how ethical issues are perceived and handled in trial organization and laboratory practice, as well as how they are expressed and discussed by different parts of the public in the focus group interviews, this chapter seeks to connect how ethical concerns are entwined with the knowledge-creating dimensions of research. It addresses not only the knowledge-creating practices of the research in the trial, but also the making of ethnographic accounts as a collaborative knowledge practice with participants. The chapter demonstrates how a so-called diffractive approach to understanding science and knowledge creation may be beneficial methodologically as well ethically, to ethnology as a discipline, as well as to cross- and multidisciplinary research endeavours and environments.

This chapter empirically shows how the value, meaning and knowledge produced in, and provided to, the making of the foetal cell suspension differs according to the vocations and tasks of the staff working within the cross-disciplinary setting of the trial. Discussing how these differences may be understood, it investigates how they are expressed and handled within

the interview and observation situations between my participants and myself when discussing the foetal cell. Understanding the process as an oscillation between closeness and distance to each other, as well as to the common object of discussion – here, the foetal cell suspension – in knowledge-creating processes, is explored as crucial. A ‘diffractive approach’ is used, in which reflexivity is instead understood as diffractivity, the potential of creation and expression of differences – materially as well as conceptually, socially and culturally.

The concept of diffraction, as explored in more detail earlier, was adopted from physical optics and first established in knowledge philosophy concerning diversity and the ‘partial knower’, by Donna Haraway (1988, 1997). In optics, it describes how waves bend and create an interference pattern, when meeting physical obstacles. The concept was later developed further by Karen Barad, a feminist physicist with an interest in philosophy and critical theory. Barad applies Niels Bohr’s interpretation of quantum mechanics and the particle/wave duality of light to explain the ways in which our choice of so-called apparatus in daily life helps bring forth reality, as well as our understanding of it, differently (2003, 2007). The allegory works well with knowledge creation in cell biology and in neurology, as well as for discussing cross- or interdisciplinary knowledge creation about what is perceived as a common boundary object (Star and Griesemer, 1989; Bowker and Star, 1999), such as the foetal cell.

The analysis demonstrates how certain instances in work or topics of conversation – either between themselves or with me as an interviewer – evoke different values, meanings and knowledge in discourse. The areas that I found to be most productive of these kinds of interference patterns were all connected to different systems of value. I saw that the value of potentiality that the foetal cells have is decided mainly by where they are located: in an embryo, in a petri dish, in a tube of suspension or in their final destination in a patient. The possibility that the embryo could have developed into a biographical person, were it to be left in utero, would then give it a very different kind of meaning and value. When the physical sex of the embryo that they are working with is sometimes discernable, the otherwise routinized work become unpleasant as a once possible trajectory for foetal cells as biographical lives comes to mind. The interviews further



show how conceptual mix-ups concerning their work occur between colleagues with different tasks and vocations in the project, indicating that these kinds of experiential differences affect the expectations, understanding and emergence of a phenomenon.

This text is to a large extent methodological, which shows how I have been working with analysing and conceptualizing the perceived ethical issues in my own research, as well as in the one studied. Even though the approach was developed as a tool throughout the thesis project, this text addresses it explicitly. I consider the elaboration of it as a methodological tool – suitable for ethnology as well as for cross- and multidisciplinary research – one of the largest contributions of this thesis.



## Contribution

### The foetal cell suspension as a bio-object

As the life expectancy of individuals in the northwestern part of the world has increased by stable numbers more or less since the era of industrialization, so have the efforts to make us as healthy and functioning as possible with and in our ageing bodies. A lot of economic capital has been invested in medical research in order to alleviate symptoms of disease, as well as to ultimately cure it or to prevent it from occurring in the first place. But as we achieve greater longevity and wealth, many more health problems will have the chance to occur in each individual during their lifetime. Longevity therefore increasingly becomes an individual as well as a societal endeavour and issue, and the techniques aiming at prolonging life and making it more comfortable increase in number and scope (see e.g. Rose, 2008).<sup>43</sup> As technical innovations in medicine allow us to target and treat increasingly smaller parts of our bodies (Rose, 2006; Liljefors, Lundin and Wiszmege, 2012), the brain with its neurons and synapses has become a central site for intervention in modern regenerative medicine. The cell transplantation trial studied in this thesis is an example of such an intervention. As has been shown in this thesis, the developments in cell transplantation research have and will produce types of bio-objects that may become incorporated routinely in practice in healthcare. These biological artefacts may then create new contexts for biomedical researchers, health professionals,

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<sup>43</sup> Four significant changes in Swedish healthcare can be outlined, of which development in technology is one. The other three are: new economic models for the organization of healthcare, an ageing population and the increased power of the patient (Hansson, 2006; Nordgren and Hansson, 2019).

patients, relatives and the public to act and think within. This thesis has explored foetal cell suspension as a bio-object that may present us with new practices and situations in the future. In some of them ethical issues will arise, while not in others.

As biomedicine increasingly zooms in on the micro level of vital mechanisms, our understanding of the body and of what life is becomes molecularized (Rose, 2006; Hansson, 2017, p.17-28 in (Eds. Hansson and Idvall, 2017)). This development is accompanied by the proliferation of bio-objects, and is not without consequences for our perception of the human and of other organisms, as well as of the body and of its parts. The sociologist Nikolas Rose argues that these developments are in fact rather a question of ‘politics of life itself’ (Rose, 2006); about harnessing pure vitality in the form of e.g. embryonic cells (Rose, 2008), than it is a matter of politics aimed at actual lived biographical lives, in the sense that state bio-politics were formerly mainly exercised (Foucault, 1997; 2007). And with a changed bio-politics follows a changed and sometimes unforeseeable medico-ethical landscape (see e.g. Zeiler, 2004; Hansson, 2017:25). As medico-technical innovations – such as foetal dopaminergic cell transplantation – quickly become mundane, normalized and widely utilized, they have the ability to redraw the boundaries of life itself (Rose, 2008) in silence.

In this thesis Parkinson’s disease as a neurological affliction and a common disease in the ageing population, is used to exemplify the change described above.<sup>44</sup> As the degeneration of ageing itself is increasingly a problem to society as well as to the individual, however, the centrality of cellular mechanisms in the brain in modern medicine problematized above is logical. Still, the innovations focusing on the cellular level of the brain set in motion renegotiations of what an accepted individual response to the threats of disease is, as well as to the possibilities of suffering and remedies (see Rose on Weber’s definition of soteriology, 2008). These strategies and practices are not universal, but rather socio-economic and

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44 There are of course many younger patients afflicted with Parkinson’s disease, as e.g. the participants of the TransEuro trial. To them, the affliction affects what is often the active years, career- and family-wise. These people are not to be included in the general reasoning here about Parkinson’s disease as connected to longevity and prosperity.

cultural products in time and space. It is therefore crucial to develop methods to better understand how affected people and their relatives relate to new medical technologies – not only as individuals, but also as members of a community. This study therefore offers insight into how some Parkinson-afflicted and otherwise affected persons make sense of medical developments in cell transplantation research, with a possible impact on their daily lives. The patients and relatives in the focus group study display a kind of ‘harsh pragmatism’ – in contrast to the non-affected laypeople, who to a greater extent can afford ‘ethical reflexivity’ (Beck, 1992). Therefore, the concept of the foetal cell suspension can be said to produce a discourse where being ill or healthy situates and influences your ethically reflexive capacity. It is demonstrated in chapter I how ‘gut-feeling ethics’ is produced in laypeople because of ‘anthropocentric concerns’ about the embryo.<sup>45</sup>

To better understand this kind of ethical contestation around the embryo, I suggest that the term *boundary object* be used to describe the function of the embryo between different communities. Most participants in the focus group interviews have very little knowledge and experience of the topic of cell transplantation research; still they can understand and discuss it – amongst themselves and with my colleague and myself as moderators – by connecting it to the embryo and the use of foetal material. The embryo functions as a boundary object to which we all can relate and refer, even if we do not have the exact same experience or knowledge of it. The clinicians and the researchers in the trial may too, in turn, be able to understand and relate to the accounts and experiences of the participants in the focus groups, due to their common referents in the embryo and the foetal material – no matter how different their understandings of it may be.

And not only is it understanding, meanings and opinions that differ when it comes to the regenerative use of foetal material. The diversity in the physical foetal material poses some challenges to the researchers in the

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45 Interestingly enough, if the ‘anthropocentric concerns’ around the *imagined embryo* of the focus group discussions, encourages questioning of the use of foetal material; the *actual foetal material in the flesh* may evoke feelings of disgust by the same anthropocentric connotations, as it is ‘abject’ to us.

trial, when trying to standardize protocols and procedures for handling it. The thesis explores how these difficulties are handled, and therefore offers a larger discussion on the limitations and possibilities of the scientific rationale as well as the technical imperative. What becoming, production and transformation can mean – materially and culturally – is investigated in different combinations of theory and discussed quite thoroughly. These contributions proudly reinforce the insights made by ethnologists previously researching this field, showing how ethics is always situated in the daily, practical work of researchers and clinicians, and how it is not only words and guidelines on ethical permits and other documents (Lundin 2012; Fioretos, Hansson and Nilsson, 2013; Hansson, 2017). This is important, given the speed of new discoveries in e.g. neurology and genetics and of innovations in biomechanics and robotics. The fleeting technological horizon and subsequent cultural interaction with it always move faster than legislation, policymaking and norms. Thus, its moving boundaries will always be as much of a challenge to society and to culture as an asset and a prerequisite for progress.

By also exploring the charged symbolism of the embryo and the rituals enacted in order to bring the ‘wasted abortion’ back to cultural order, in article III, the thesis also offers insights into how cultural transformation requires an oscillating movement between consensus and contestation concerning symbolic conceptualization transgression – no matter how dependent on material conditions they may be. The making of the cell suspension produces ethical ambiguities due to the foetal origin of the material, and the thesis makes visible how some researchers handle the subsequent dilemmas by different emotional, cognitive and discursive strategies. The ‘embryonic ambiguity’ of the foetal material is handled by ‘pollution behaviour’ (Douglas, 1966), helping to usher the aborted embryo back into cultural order by making it a resource in regenerative medicine. The ushering done by the researchers, in turn, provides them with a liminal role between the communities of researchers, patients and relatives, as well as a personally unaffected ‘public’. An interesting reflection here is that while the foetal material or embryo is welcomed back into cultural order when made into a regenerative cell suspension, in the form of a bio-object it has now been given the (at least theoretical)

ability to cause disorder again, by transgressing borders of nature and culture and of individuals when being transplanted (Lundin, 1999; 2000; 2002). These insights taken together offer a basis for better understanding the ambiguous role that the embryo is given in regenerative medicine, and thereby also emphasize how medical science is largely dependent on cultural processes of symbolically binding materiality with cultural categories. They hopefully also contribute to creating fairer knowledge of the cultural skills and symbolic work required and employed by biomedical researchers in practice.

The planning of interventions in the human brain therefore arguably needs an amount of cultural skill, beside the neurobiological and logistical skills. Still, the planning of trials and of research unavoidably produces negotiations in and of time and space. These negotiations may be seen as indications of the possible impact of the planned intervention, as well as of the intricacy of the human brain and of foetal cells. The delays of the trial, discussed in detail in article II, are in themselves strategies in ethics, as much as consequences of practicalities. Assumptions of nature and culture are inevitably written into the trial in the form of instructive protocols and ethical permits, and ‘black-boxed’ (Latour, 2005). Many of them are as prescriptive as they are descriptive. ‘Unboxing’ too many prescriptive assumptions risks bringing the trial to a halt and challenging the important consensus of planned progress in the trial, and must therefore be avoided. The delays are partly a product of this avoidance. Some of the delays may arguably also originate from the fact that the foetal material practically challenges some prescriptive assumptions about it in the protocols. As a boundary object for the different professionals involved in or with the trial, the foetal material needs to have a fair amount of vagueness and transformative properties, even if that means resisting being put into one unifying category. Still, ‘un-boxing’ some of these assumptions made of e.g. foetal material or the donating women is an important practice – for ethnologists and others – seeking to understand how ethics is done in practice, in their own daily work or when researching other fields.

## Diffracting knowledge in cross- and multidisciplinary settings

The thesis demonstrates that value, meaning and knowledge of the foetal material as a boundary object, and of the cell suspension as a bio-object, is indeed diffracted differently due to vocational differences among some research staff in the laboratories (article III and chapter IV), as well as between them and patients, relatives and non-afflicted public (chapter I). As processes in medical science are constantly being standardized with the help of legislation and procedural documents, there are – and will probably always be – deviations between each participating research site. This is because there are different people, with different experiences, cultures, mind-sets and bodies that work in them. The fact that the procedures even take place in different settings at different times makes a difference. This is demonstrated in Article II, when Emma once needed to travel to a participating trial site in Britain, in order to fully understand how the cell refinement procedures differed there and why they produced different outcomes in cell survival, as it was not discernable from the protocols.<sup>46</sup>

Proceeding from Karen Barad's agential realism (2007), we can learn from quantum physics that everything is part of the apparatus, or of the experimental set-up, when any knowledge is made. Adding the concept of boundary object to the diffractive reasoning around the embryo and foetal material helps to highlight the role of the cell suspension as the central phenomenon produced. As there is no such thing as merely context, everything counts as influential for an outcome. This means that all knowledge and all phenomena are specific to a time and a place. In a way, the point that all knowledge is situated (1988) and circumstantial is rather reinforced by the choice of my empirical samples and their limitations. Still, that all knowledge is specific does not mean that it is not transferable and translatable. Otherwise, evidence-based science would not be able to

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<sup>46</sup> It also became apparent when taking care of the foetal material 'as soon as possible' in one site turned out to mean the next day, while in Emma's concept of practice it had a very different temporality in which it meant up until maybe an hour later. This instance was retold to me by Emma, and occurs in my field notes but not in the articles or chapters comprising this thesis.



make knowledge that represents or intervenes (Hacking, 1983). Still, the findings point to some of the challenges of making nature into culture on a cellular level, as well as the hardships of standardizing a force of life itself. The foetal material differs between embryos, and it is difficult to measure all parameters determining its 'quality' and character. Therefore, outcome in cell count and subsequent innervation in a transplanted brain is hard to foresee, making standardization and homogenization of material as well as procedure problematic. Proceeding from knowledge as situated and from biology and nature as difficult to standardize, a larger sample of research sites or researchers in my study would probably have rendered just as many different results as participants.

The diffractive approach used in this study (chapter IV) is a well adapted tool for investigating such diversity in knowledge production in different contexts. It allowed the foetal cell suspension to be a common boundary object for diverse knowledge creation between the participants and me. Putting your 'ethnological glasses' on is an expression partly referring to an ethno-methodological move where researchers un-familiarize themselves with the object of study by different techniques. The goal is to make the mundane seem exotic. During my fieldwork, I had to put these glasses on my participants instead, in order to make the aborted embryo and foetal material feel alien to them. This way, we managed to look at and explore the foetal material from different perspectives, still offering our own individual conditions and affinities as a point of departure for knowledge creation (see also Mellander and Wiszmeg, 2016). Performed this way, the construction of ethnography may be developed into an ethics-in-practice involving cultural analytical work by researcher as well as 'researched'. As you often share boundary objects but not the conceptions of them – or if your boundary object fits in more than one category – this move allow differences in understanding and valuing the common object to be traced and discussed – not only in the subsequent academic reports or accounts, but in real-time research and fieldwork. Sharing knowledge at the core of its creation together with your participants is a good way of 'giving back to the community' – even when the community consists of a group of highly skilled biomedical researchers. I therefore believe that putting the methodological side of the diffractive approach to work when researching

other researchers or professionals could prove highly fruitful for all parties involved. As many research environments today are often highly multidisciplinary, the gain of the diffractive approach arguably grows as the communities sharing boundary objects and constructing bio-objects multiply.

The number of unforeseen ethical issues and encounters grows too, as bio-objects are being rapidly invented and utilized in biomedicine and in medical care, thus intervening in, and enacting, a kind of ‘politics of life itself’ (Rose, 2006). Therefore, I believe a diffractive approach may be of value when researching the entanglement of knowledge, culture and ethics in and between different groups of interest and experience. Utilizing this approach on issues concerning knowledge production may also be viewed as an important humanistic attempt at approaching the ‘critical friendship’ suggested by Nikolas Rose (2013, Hansson and Lindh, 2018), as a basis for interaction between the natural and the social sciences. The difficult part of this kind of friendship, he argues, is that “it requires not just a rethinking of experimental practice, but a rethinking of the object – the object that the experiment is directed towards” (2018:117). This thesis offers a rethinking of foetal material as a boundary object and of foetal cell suspension as a bio-object. It offers an analysis of them as objects of study and production in regenerative medicine, as well as of the conditions of, and possibilities in, producing knowledge about them. More generally applicable – it offers insights into how to *think together* with your participants, yet allowing differences to emerge. Either tightening or loosening your common grip on the topic of discussion or object at hand, may achieve this strategic shift in perspective.

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# Appendices

## Interview guides

1. What is your main task in the TransEuro project? Describe it. What is it that you actually DO? What other tasks do you have, that you would consider less significant?
2. What do you consider to be the main aim of the TransEuro project? What are you trying to create?
3. How do you believe you contribute to this aim?
4. What do you believe is the biggest threat to the success of the TransEuro project?
5. What do you believe would be crucial to its success?
6. In what aspects of the project do you believe the word 'quality' to be most crucial?
7. What is it that TransEuro is trying to create evidence of?
8. What objects and procedures within the project do you think are most connected to this creation of evidence?
9. What objects and procedures involved in *your* daily work in the project do you think are most connected to the creation of evidence? (How is this connected to randomization and/or consensus?)
10. What would you consider to be sensitive aspects of your work? In what way? Why? Is this considered so by yourself or by others?
11. Do you have knowledge of what is being done to the material throughout the entire process of the project? Why do you/do you not have this knowledge?

12. What do you consider the cell suspension to consist of?
13. Do you have any thoughts on its origin? Do you think of it actively while working?
14. When creating the treatment-to-be, a kind of potentiality of the neural cells is transferred to the brain of the rat or patient. Do you view this potentiality of the cells as inherent to the foetus, or as created throughout the process?
15. How does your work help transfer this potentiality?
16. FOR JAMES: When the suspension has been transplanted to rats, and the cells have been joined with the tissue of the striatum in the brain – in what ways are the original cells still present in the brain? (Can the original cells be distinguished from the neurons being formed? If in some cases neurons do not form, can you then locate the original cells?) Would you consider the cells distinguishable from the other materials and substances present at different times, such as the newly formed neurons, the hibernation fluid initially inserted, or the immunosuppressants and the protein colour tracking? Why/not and how?  
FOR EMMA: When in the process do you experience that the foetal cells stop being a part of a foetus? When does the material go from being foetal material to just material or cells? When does it start to be a cell suspension? What tasks in your work do you believe aid this transformation? Would you consider the cells distinguishable from the other materials and substances present at different times, such as the hibernation fluid initially inserted to the suspension?
17. FOR JAMES: Do you have any routines for controlling the less transparent procedures in the process, such as the injection of suspension into the rat brain with a metal needle? How do you handle the insecurity of whether the right amount of cells has been injected in this process?  
FOR EMMA: Do you have any routines for controlling the less transparent procedures in the process, such as what happens in the cell countess or in the incubator? How do you handle possible insecurities? Are there instances in the process where you experience the conceptual differences between entities or substances (i.e. what we call and read into things) to be bigger than the material differences between them? Or vice versa? Do discrepancies occur, and if so, how, why and where?

18. How are these discrepancies treated? Are they addressed, are measures taken, or are they simply overlooked/ignored?
19. Do you believe that these discrepancies (whether handled or not) have consequences for the project? In what way?



## Original articles









## Chapter III

### Medical need, ethical scepticism: clashing views on the use of foetuses in Parkinson's disease research

Andréa Wiszmeg

'And if it's going to die, that little fetus, then it doesn't matter to me at what stage.'  
(Patient on the use of foetal neural cells versus the use of embryonic stem cells)

This quote neatly captures a central difference between patients and non-affected respondents in a focus group study of attitudes towards foetal neural cell research and therapy for Parkinson's disease. The patients of the study displayed a pragmatism verging on unconcern in the ethical issues concerning the fetus and its human status; this to a considerably higher degree than the non-affected respondents, who, on the contrary, seemed quite preoccupied by such issues.

Parkinson's disease is a severe neurological disease with symptoms such as rigidity, slow movement, tremors and sometimes depression and dementia. The aim of this essay is to investigate how patients with this disease and non-affected individuals reason about research that uses foetal neural cells. The focus is on their thoughts about what is ethically defensible in the search for treatments for Parkinson's disease.

As such, it falls within the framework of focus group interviews conducted in Sweden as part of the EU project TRANSEURO (<<http://www.transeuro.org.uk/>>).<sup>1</sup> One of the key findings of the Swedish focus group study is that the participants' ethical attitudes closely correlate to their relation to the disease. This means that whether you are afflicted or in other respects affected by the disease or not will be highly relevant for your ethical stance. I will argue here that individual circumstances also largely determine the motives and effects of ethical reflection. I also elaborate on the role of gut feeling in ethics (see Lakoff & Johnson 1999; Lundin, this volume) and how it relates to what I would term anthropocentric concerns.

Ulrich Beck's concept of individual ethical reflexivity in late modernity (1992) serves here not only as a theoretical point of departure, but also as a point of discussion itself. This latter is a consequence of the results of the study confirming some general trends that Beck points to, but also revising some of them in addressing the issue that individual reflexivity needs to be related to one's experiences of, in this case, Parkinson's disease. My argument that one's relation to the disease fundamentally affects one's motives and effects of ethical reflection serves to nuance the generalizability of Beck's theory.

#### Parkinson's disease

Parkinson's disease is caused by the death of certain nerve cells in the brain that produce the signal substance dopamine. Neural cells harvested from aborted fetuses have the potential to develop into dopamine-producing nerve cells in the patient's brain. The available treatments today target only the symptomatology of the disease, but research on foetal cells aims at finding a potential cure (<<http://www.med.lu.se/bagadilico/>>;

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<sup>1</sup> The focus group interviews were conducted by Prof Susanne Lundin, Markus Idvall, and Andréa Wiszmeg of Lund University. The theme of the interviews was the use of foetal neural cells in researching treatments for Parkinson's disease and the ethical implications of this research.

<<http://www.transeuro.org.uk/>>). This has given many patients with Parkinson's disease and their relatives renewed hope, and the development of this technique is quite well known to many in contact with the disease.

Trials with foetal neural cells on patients with Parkinson's disease have been carried out since the mid-1980s, primarily the US and Europe, with varying degrees of success reported due to many complex factors, such as the pureness of the grafts and the age and severity of symptoms in the patients implanted (Woodbury 2010; Shannon 2009). The status of the method is still today at the trial stage and has not been applied in clinical use as therapy. Current trials in facilitating this method are mainly aimed at developing a protocol for a future use of stem cells. The use of foetal neural cells remains at the research stage. The main reason for this change of focus to stem cells is due partly to the very varied results of the implantations. It is also important that there is a limited supply of aborted foetuses, making it almost impossible to transfer the technique to clinics for the large-scale treatment of patients.

Even if well known to patients, the vast majority of the general public have probably never heard of this specific therapy development, let alone the use of this specific cell type. Although Parkinson's disease in itself is well known to most people, the process of developing this therapy is not. However, since the origin of the cell is something as familiar but at the same time controversial as an aborted foetus, it makes possible a more general interest in the cell's therapeutic development and use.

### **The TRANSEURO study**

As described on their website (<<http://www.transeuro.org.uk/index.html>>), 'TRANSEURO is a European research consortium with the principal objective to develop an efficacious and safe treatment methodology for Parkinson's disease suffering patients using fetal cell based treatments'. Its stated research objectives, which include the social sciences and representatives from the humanities, are 'To develop a protocol that can serve as a template for all future clinical trials in the cell therapy field including stem cell-based therapies and the ethical implications and ramifications of such work.' To target the latter objective, a focus group study consisting of both patients and non-affected respondents was conducted in Germany, the UK, and Sweden. Ethical considerations in the research of therapies for Parkinson's disease, the anticipated form a future therapy may well take, and the research done to develop the same were discussed. The political scientist Herbert Gottweis, a member of the ethical board of TRANSEURO, initiated the focus group study, and designed it together with Ursula Gottweis. The focus group study should be understood as a response to clinical trials designed to achieve progress in protocols to be used for future stem cell research, which are planned to take place in the UK and in Sweden in the autumn of 2012.<sup>2</sup>

In the course of the Swedish focus group interviews, we experienced how patients and non-patients seemed to have a different understanding of the meaning, context, and use of the foetal neural cell due to their different experiences, needs, and expectations of the development of this therapy. This led me to investigate further *how* this was expressed by the participants; how the process of legitimizing one's opinion was constituted by relating differently to the cell and the therapy—using them as a surface on which to project negotiations of ethical and moral concepts and values. This is what will be focused on in the present chapter. I have chosen to explore these processes by viewing them as expressions of Beck's concept of late modernity's individual reflexivity (1992).

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<sup>2</sup> For details on the partners participating in the project's clinical trials, see <<http://www.transeuro.org.uk/pages/partners.html>>.

According to Beck, our times are characterized by constant and increasing demands on the individual to reflect upon one's behaviour and its possible consequences in a more and more ethically opaque global society; demands that emanate from government bodies and companies alike, underlining one's individual responsibility for a plethora of unforeseeable consequences. This, in an age when the choices one makes are often seen as part of an important personal branding, so running the risk of equating possible failure and unwanted consequences with personal failure.

Starting from this supposition, it would be reasonable to assume that initiating a study that makes the participants reflect on something as culturally and morally charged as bodies as subjects, objects, and commodities might well spur them to greater individual reflexivity. Even more so since those commodities are in part regulated by supply and demand in a controversial surgery and therapy development. In what follows, I investigate whether the added conundrum that some of those sought-for body parts (or rather, tissues) were once a potential life in its entirety, makes for an ever more controversial issue.

### **The power of categorization**

It is risky business, analysing attitudes and opinions merely by ascribing the participants of a study to a certain main category, which in the specific context has been decided beforehand to have value and implications for the study. By doing this, many intersecting interests and experiences are lost or misunderstood. Even if one inevitably needs categories in order to conceptualize trends and tendencies in certain data or fields, an awareness of the problems and shortcomings of doing this is needed.

Biomedical researchers are, for instance, not only professionals and researchers. They are also members of the general public, with much the same normative, common moral standards for their time and place, in addition to their varying personal circumstances outside the laboratory. This is arguably applicable to patients as well, being part of a collective society with certain norms, values, and understandings, but at the same time forming a community of patients with a strong shared interest—their well-being and ultimate survival.

This led me to investigate how patients from the focus group study relate to the foetal cell and the therapeutic implant that can be derived from it. This has been done in comparison to the non-affected respondents in the same study. Further, I relate it to Lundin's study (this volume) of the ethics discussion group among nerve- and stem cell researchers, by discussing ethical reflexivity and its premises between the categories of 'patient', 'non-affected' and 'researcher'. I have set out to locate and problematize the various interpretations, understandings, and opinions that stem from different individual experiences and expectations when discussing neural cell therapy developments and clinical uses. I will explore how the participants of the focus groups use the concept of foetal neural cell therapy for Parkinson's disease as a surface on which to project their ethical, moral, and relational values.

### **Methods and theoretical considerations**

In conducting the focus groups interviews, we used a thematized script with minor differences for each group of interviewees.<sup>3</sup> The script, which was used in all the participating countries in order to ensure full comparability, targeted a number of themes and included some specific questions on the topic of Parkinson's disease and therapy development. Much of the ensuing discussion was given over to therapy development and the application of foetal neural cells.

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<sup>3</sup> The script was originally designed by Herbert and Ursula Gottweis; the version mainly used in Sweden was modified by Markus Idvall and Andréa Wiszmeg.

When creating the empirical material presented in this essay,<sup>4</sup> the quotes are sampled from discussions concerning (*Question 1*) opinions and knowledge about the use of foetal neural cells; (*Question 2*) attitudes towards sham surgery (of which more later) ostensibly using this therapy, and on possible participation in a sham-controlled trial; and (*Question 3*) respondents' views on any differences in the safety and ethical implications of the development and use of foetal neural cells in comparison to embryonic stem cells.<sup>5</sup> Question 2 was originally treated as two separate questions during the focus group interviews, but in the course of the interviews it was repeatedly found that the non-affected respondents felt uncomfortable discussing their own imagined participation in a sham surgery trial, since they found it impossible to envisage such a situation, and we accordingly decided to merge the questions. Indeed, in order to be able to discuss the issue of individual ethical reflexivity and its prerequisites, this combining of the two questions into one and the comparison of their respective answers also serves a purpose, for it highlights how respondents position themselves in relation to experience and need. What follows are thus the responses of individual subjects with different possibilities for ethical reflexivity.

Assuming the validity of Beck's claim (1992) that late modernity produces individual ethical reflexivity, I show that this tendency is visible in the material produced by this focus group study. Still, my use of Beck's concept here is not without reservations, for I would maintain that ethical reflexivity is something which has greater or lesser meaning, impact, and room in individuals' lives in relation to their overall situation. Thus I start from the argument that the individual reflexivity of late modernity as discussed by Beck (1992) is to be seen as an effect with a temporally and spatially limited 'natural room' in the individual's life, created by specific circumstances where individual, societal, and technological parameters and demands entwine. I understand such reflexivity as being triggered by external forces such as sets of cultural rules, or a system of societal or political protocols (see Habermas 1987, for the concept of systems and life-worlds), but which nonetheless can have a great impact on both individual and society. Still, as will be seen, there seem to be instances and circumstances where 'simpler' and more pragmatic views override the subject's ethical reflexivity.

### **Foetal neural cell use**

I address three themes that were discussed in the focus groups to gauge the attitudes of the participants. I found that the question of *Opinions and knowledge about the use of foetal neural cells* functioned as an opening onto the complexities of this form of therapy development. The participants were encouraged to speak freely about their own views on cell and therapy development—whether they had any scientific knowledge of it or not. Many of the participants emphasized precisely their lack of knowledge or understanding of these things as something that made them poor representatives or participants. Once the obstacle of the respect accorded by participants to the authority of science was surmounted with the help of a

<sup>4</sup> Neither the entire project nor the full set of Swedish data and findings are taken up in this chapter, for though broadly indicative they would render many of the conclusions tentative. When quoting from the material, for reasons of space I have not given the exact phrasing of the question or general discussion, but I do indicate the theme of the discussion.

<sup>5</sup> The foetal neural cell is harvested from what is defined as a foetus, nine weeks or more from fertilization, and therefore by definition is taken from aborted fetuses. The human embryonic stem cell is taken from an embryo, which is less developed than a foetus, and harvested from embryos left over from *in vitro* fertilization. A stem cell has, because of its low grade of definition and development, a very large potential for developing into all kinds of cells (being totipotent), whereas foetal neural cells are already defined specifically as neural cells. What compromises the future use of human embryonic stem cells is that, by virtue of their totipotency, they are harder to control cell growth-wise, which can result in cancer growth; what compromises the use of foetal neural cells, meanwhile, is the question of acquiring the correct amount of foetal tissue.

shared ignorance of many technical aspects on the part of both participants and us humanist researchers, the discussion about attitudes and ethical issues in the use of foetal neural cell tissue could begin.

It was striking that many of the patients interviewed took a very pragmatic line on both the status of the cells used and the basis on which one had the right to use them (see Lundin & Widner 2001, on pragmatism in xenotransplanted patients). Even given a certain exaggeration in order to make a point, the following quote highlights the attitude that if parents have the right to have an abortion, then the material of the foetus no longer belongs to them, nor does it exist in its own right:

But if you decide that this foetus is going to die, then it would be strange if you had opinions on it being used for something positive, the dead foetus. I don't get that. I don't see any problem with that. People can have an abortion if the timing is wrong; maybe they're going on holiday instead of having a baby. It can be any reason why they choose to kill their foetus. If they choose to kill their foetus then it has to— It can't be any problem benefiting from the dead foetus. (Patient on *Opinions and knowledge about the use of foetal neural cells*)

This Parkinson's patient ascribes brutality to the woman or couple choosing an abortion, choosing to highlight that the abusive act in this process is not the use of the foetus for research, but rather the relative trivialities that the informant supposes can prompt an abortion. This also feeds a utilitarian argument, since it would be wasteful to not use this tissue. The metaphor of 'to waste', as opposed to 'to save', is freighted with culturally unambiguous negative and positive connotations respectively (Lakoff & Johnson 1999). Such value categories make arguing about the contents to which they are attached almost impossible.

The ways in which these kinds of arguments indirectly help to legitimize research involving aborted fetuses is also worth attention. It is highly probable that this legitimization of the use of foetal tissue in research is more of an effect than is it a cause. The position from which a patient in need reasons is not—as in the case of a non-affected person—a hypothetical one, but instead a very real, serious, and immediate experience. All the same, the outcome is an ongoing legitimization of the research with the main arguments being, as above, that the material is already there and it would be a waste not to use it.

What comes out in accounts given by the non-affected respondents on this first broad topic, and which also continues to be visible throughout the study, is a kind of undefined uneasiness when participants unwillingly find themselves having to negotiate societal gains and losses from a utilitarian perspective:

Absolutely! ... But then, when I read question number two; 'Could you imagine to—' ... read this again and be reminded that I actually read this before—how many (fetuses) it takes. Then I feel that you immediately have this thought with 'But how is this carried out?' ... But at the same time, as you are saying, if it helps a severe disease of course it's good. But still— one needs a moment, to some extent, to think about it. (Non-affected respondent on *Opinions and knowledge about the use of foetal neural cells*)

The fact that even life at its most fundamental level can be valued from a socio-economic perspective is not easily processed, but still unavoidable in addressing these kinds of issues.

### **Sham surgery**

During the development of a much-awaited future therapy with foetal neural cells for Parkinson's disease, there have been certain trials done involving so-called sham or placebo surgery. This means that, in order to attain the scientific standards of evidence-based medicine, trials were designed to involve patients who received no actual cells, but ostensibly underwent the same surgery as the patients who received the therapeutic implant of the cell. This procedure—which should not be thought standard—has been much debated, and is

considered unethical by many surgeons and researchers. Many argue that such a procedure is wholly unnecessary in meeting the scientific standards of evidence-based medicine, while some maintain that it is indeed essential (see, for example, Galpern et al. 2012). Even if not standard, such trials have been done and still have their advocates, which makes discussion of such a procedure relevant.

The quotes below, sampled from non-affected participants' responses to the question of *Attitudes towards sham surgery using this therapy and possible participation in such a trial*, reflect their prolixity compared to the brevity of the responses from the afflicted patients, reflecting a need to elaborate on this topic. The patients gave shorter, more pragmatic, and more concise answers when asked if they would consider being part of a sham trial than did non-affected participants when asked either to imagine having to choose or what their attitude was in principle:

Well I'd be prepared to run a greater risk in one of those (medical trials), if I knew that it could lead to me being cured. (Patient on *Possible participation in a sham-controlled trial*)

The relief of symptoms and a possible cure seem to be the natural focal points for the afflicted, in relation to which all other risks and ethical considerations must be measured. Still, in this measurement, the details of the risks and possible consequences are most often downplayed or passed over in the silence. The risks are left unspecified. Is this done in order to handle possible risks as part of one's own decision while remaining focused on the possible cure?

I would definitely, I thought about this and then I thought that this risk is worth taking to get rid of this ... And that membrane that is stretched over your head, it would be nice to get rid of that. That's how I feel anyway. (Patient on *Possible participation in a sham-controlled trial*)

While the patients kept the reasons for their personal attitudes short and concise, non-affected participants had a tendency to elaborate on the many different aspects to be taken into consideration and that kept for their opinions on the topic on a more general level.

Interestingly, there was a great unwillingness on the part of the unaffected respondents to try to imagine themselves as being afflicted with Parkinson's disease, envisaging what it might be like to make decisions on being part of this kind of trial based on actual bodily experience of the disease. This was either based on the flat impossibility of imagining such circumstances, or, on a more idealistic note, that on the ethically insensitive or even indefensible reasons of doing so:

But this also requires that we can imagine what it's like to have Parkinson's, and kind of how desperate you would be. That's very, very hard. I have a very hard time putting myself in the shoes of— and that's the first criterion to be able to make a stab at this. But having a sham group, that's, that's objectionable! Not everything can be done in the name of science. This would be wrong from a— hmm— (Non-affected respondent on *Attitudes towards sham surgery ostensibly using this therapy*)

Except from the reluctance to try to imagine oneself as being afflicted—maybe for fear of misunderstanding the motivations of a person with Parkinson's disease—something else is also visible in the account above. Something even more undefined, shapeless, and defiant of proper articulation.

A minority of non-affected participants tried to make themselves acquainted with what could (according to them) be possible considerations for patients facing a decision on whether to participate in a sham-controlled surgical trial. The factors that one non-affected person pondered at length were age and life span:

It might depend on your age [whether you'd get into a trial with sham surgery or not]? If you were younger and had a more time left to live— then you might, if you're living a poor life



with severe disease, maybe then— they might view it differently? But I don't know. You're young so you might have a different view? You cannot possibly know how that is. But I think you'd be willing to take more chances, 'I have to get well, I am going to live for a long time'— There are many people our age who get cancer for instance and don't want to do anything about it. They believe they've lived long enough so now they let it take its course. So— I think you should ask people who are somewhat younger. On this topic. They might be of a different opinion. (Non-affected respondent on *Possible participation in a sham-controlled trial*)

Age and different phases of life are also factors mentioned by some patients when negotiating the risks and possibilities of treatments in general, of foetal cell therapy, and of the 'gamble' of participating in sham-controlled surgery trials. Having small children to take care of; being in good health except from Parkinson's disease; or feeling there was 'nothing left to lose' in resorting to dangerous and risky treatments at high age: all these factors varied among the afflicted participants. Age as a common denominator for the negotiation of risks and possibilities amongst both non-affected and afflicted was a noteworthy feature, while (as already noted) other specific risk factors and more abstract ethical issues seemed to be downplayed by the afflicted. The age and life phase factor, meanwhile, seemed to be something with a direct applicability to the individual person's life—patient as well as non-affected.

### **Foetal neural cells versus embryonic stem cells**

The discussions about *Views on any differences in the safety and ethical implications of the development and use of foetal neural cells in comparison to embryonic stem cells* generated extremely interesting material that highlighted a number of issues. There were some major observable differences in the concerns of the patients and the non-affected respondents at the use of foetal neural cells and the development of therapies thus far, although, as will be shown, the differences should be considered an effect, rather than the cause, of their different circumstances in living with and relating to Parkinson's disease.

There is also reason to return to the subject of the pragmatism of the patients. In the conversation among a group of them, once again the possible problems of the material and its origin are downplayed—even when asked explicitly to elaborate on the ethical differences in the implications of foetal neural cell use in comparison to stem cells:

- No, not if you can be helped by it. I don't think it matters, because if you can use them for something, then maybe it would be just as good with foetal cells as with embryonic cells. And if it's going to die, that little foetus, then it doesn't matter to me at what stage.
- Then it's more a question of what's easiest to access.
- Yes, the quantity. (Patients discussing *Foetal neural cells versus embryonic stem cells*)

When viewing this discussion in relation to how some non-affected participants reasoned on the ethical differences implied by the use of foetal neural cells as against stem cells, another picture emerges:

I have something against this thing with the foetal cells— I don't know why, but it's just like there's something— that doesn't feel good. ... Well I think a lot about the donors of it— this, there must be someone giving their permission for it? Yes. ... There are emotions involved there. (Non-affected respondent on *Foetal neural cells versus embryonic stem cells*)

Obviously there is something unsettling about this whole procedure of involving donors, emotions and all, in giving permission for the donation. And besides the donors' feelings and their emotional attachment to the foetus, it seems as if there is something more abstract involved that the non-affected respondents struggle to put into words.

The question of whether a foetus belongs to someone (most often thought to be the pregnant woman) and is therefore an object, or whether it should be considered a subject in its own

right, has been debated between pro-life and pro-choice activists for decades. This problematic is not stated, and may not even be conceptualized, in the quote above. Still, I would suggest it is this that is partly the cause of the unease. It seems as if it is the status of the foetus, or rather its ‘non-status’, which makes it simultaneously uncomfortable and difficult to talk about; difficult not only from an emotional and ethical perspective, but also conceptually. The words are lacking. The double role of the foetus as belonging to the woman or both parents but still being a possible life in its own right is part of creating this uncertainty. But there are other factors too, such as the where the borders of humanness lie (see Lundin 1999: 5–31; Haraway 1991, 2008):

That [human embryonic stem cell research] would be better— Than this foetal— neural cells. ... Well, it’s not that far developed as a foetus. It’s not fun to— ... Yes, because it’s the parents, I mean then it is a life, it is a foetus. (Non-affected respondent on *Foetal neural cells versus embryonic stem cells*)

The established but arbitrary definition distinguishing medically between an embryo and a foetus on the basis of its development, I would argue, has the cultural function of upholding these borders of humanness.<sup>6</sup> The idea of a point in time of development before which the embryo is something other than human, a ‘thing’, seems to help in preferring and legitimizing the use of embryonic stem cells over foetal cells:

I think there is a lot of difference between a foetus and a foetus to come! ... Yes, and these ten cells [constituting an embryo] are not sitting around and thinking how beautiful the world is or something like that— no I don’t think so. (Non-affected respondent on *Foetal neural cells versus embryonic stem cells*)

### Legitimizing science

A study of neurological researchers participating in discussion groups on biomedical ethics (Lundin, this volume) has showed that the participants displayed a desire to gain legitimacy for the research practices in which they are involved. This was expressed in how the participants related to the ethically sensitive issues of cell procurement, origin, and context. By drawing the conclusion that the non-affected and patients alike accept and support the ethical foundations on which the development of these treatments rest—based on the fact that they demand the research and ask for cures—they found permissible ethical support for their work. The legitimizing arguments also very often rested on—broadly defined—utilitarian perspectives advocating the sacrifice of one life for the gain of many others. This must be understood in contrast to how the arguments of the sanctity, integrity, and non-profitability of the individual body (see Berglund & Lundin 2012) are otherwise related to. These are the kinds of values referred to when gut feelings come into play in ethical reflections.

My analysis of the TRANSEURO focus group study shows that some Parkinson’s patients resort to the same kind of arguments as the researchers in Lundin’s study when seeking to justify research that is seen as generally ethically sensitive—both by themselves as cultural and societal beings and also by non-patients. This is expressed in statements where, for example, the normative dichotomy of saving or wasting is brought into play. This is done in talk of the foetal cells as a material that is ‘just there’, and that the morally dubious thing to do would be to not use it, since that would be ‘to waste’ it.

The bald pragmatism of many of the statements made by the patient participants led me to wonder whether dogmatic and absolute views are a luxury affordable only by those whose lives are not in jeopardy. Is being an ethical subject in reality a privileged position? It would

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<sup>6</sup> The impregnated cell cluster is considered an embryo for weeks 2–9 of pregnancy, after which it is called a foetus.

be a far stretch to claim that the ethically reflexive subject of Beck's theories on late modernity (1992) cannot be a person who is afflicted with a severe disease that is so heavily researched as is Parkinson's disease, on which the full arsenal of biotechnology is brought to bear. Of course, our integration as cultural and social beings in our contemporary world grants us the ability as individuals to reflect on such issues, yet, I would argue, what seems to be the main motives of the afflicted—survival, recovery, or at least remission—to some extent diminish the purpose and possibilities of their ethical reflexivity. Attitudes, ethical reflections, and morale are situation-bound (see, for example, Lundin & Idvall 2003; Wiszmeg et al. forthcoming 2013), and, as former studies have shown (Lundin 1999), pragmatism most often beats ethical reflection at times of need. Further, it is remarkable that in this case it seems to be both patients and researchers intent on curing Parkinson's disease who are the 'least free' reflexivity-wise, since both groups are in need of a pragmatic view to legitimize research where the sensitive issues of the origin and integrity of the material used are challenged.

### Gut feeling ethics

Gut feelings as ethically guiding sensations or phenomena are often thought to be subconscious, mythical functions inferior to the rational mind, and for this reason are just as often disregarded by our cultural and social selves. This is problematic, because it circumscribes the chances proffered by gut feelings to really examine in detail what this signal tells us about our cultural value system, its foundations, and our position within it.

The uneasy but abstract feeling that something is just not right is observable at several different moments in the material. Even if not argued for consistently or 'rationally', *something* is making the non-affected respondents express very intense emotions and firm attitudes. *What* is wrong is very often left undefined and unexplained: a gut feeling is often left unelaborated, and is usually not even reflected upon.

A plausible question, even if not advocating a rational-minded analysis is what *is* it that gives people the gut feelings upon which ethical considerations and convictions are often based? What process going on between the individual and the surroundings is it that our gut feeling is supposed to signal to us about? Or, rather, of what processes is a gut feeling a product? If it is taken kind of to be a type of cultural instinct that signals values and collective norms (Lakoff & Johnson 1999) on a precognitive level, we also need to view it as pre-discursive. The gut feelings referred to in the material are simple in language and immediate in response. It seems as if there are gaps in our common language that by no means lack in meaning. This specific muteness is, culturally speaking, alarmingly loud.

Of course, the response to any specific question on any given ethical issue will differ a great deal depending on cultural, economic, and age- and gender-related positions and on the temporal and spatial circumstances of the responder. In this study I have not adopted a specifically intersectional perspective (see, for example, McCall 2005), but rather have focused on the categories of researchers, patients, and the non-affected. And one trend found in the material was that the non-affected respondents to a far greater extent seemed to be the ones hearkening to their gut feeling that something was 'wrong' with these processes.

I discovered that, however undefined it might be, a gut feeling was often matched by hesitations over the gradual difference in development between an embryo and a fetus. The implications of the definition ranged widely according to the perspective: from parenthood, via personhood, to legal status and individual rights. I use the term 'anthropocentric concerns' when considering the boundaries of humanness: a crucial aspect of the specific ethical issue of the human fetus. The human fetus is such a powerful symbol of 'the human' and yet so

alluringly alien. Drawing the line between an embryo and a foetus seems to be of high importance for maintaining cultural order.

What made me connect the ethics of gut feelings with the concept of anthropocentrism were quotes illustrating how gut feeling in ethical considerations often coincided with conversations or discussions in the focus groups concerning the boundaries of humanness.<sup>7</sup> Those conversations, at least within the focus groups of non-affected respondents, revealed a structural negotiation of what is and what is not acceptable action towards *human* life—thus struggling to draw a sharp line between what is human life, and what is not (see Haraway 1991, 2008; Lundin 1999). Such categorizing work was for instance visible when one of the non-affected participants stated that there ‘is a big difference between a foetus and a foetus to come’.

Inevitably, theoretical questions arise of the grounds on which something is judged human or not, and what practical implications this distinction might have. Even if not stated as such by these participants, I would argue that what shapes their vague sense of unease is what I call ‘anthropocentric gut feeling ethics’. Revisiting the idea that the non-affected enjoy a privileged position in affording to negotiate risks and possibilities, it is instructive to compare the patients’ pragmatic views on the human status of the foetus in relation to its pre-natal development, with those of the non-affected respondents in the study. For some patients there is neither room nor need for a clear distinction between what or who is human (enough) and what or who is not. Still, it cannot be overstressed that it is probably a situation-bound, temporary step outside the ‘anthropocentric thought box’ even for these people.

Still, this lack of anthropocentric concern on the part of the Parkinson’s patients in the study leads me back to Ulrich Beck’s concept of the ethical, reflexive subject. Even if seen as exceptions to their normal ethical ontology, the choice of being pragmatic rather than ethically reflexive can be seen as a strategy for coping with a difficult situation. The relational ramifications of the subject and its dependence on research advances, combined with the fact that one’s own life might be at stake, are parameters highly influential on the conditions of the subject’s actual reflexivity.

### **Affording ethical reflexivity**

So, who in this context have the best opportunities of being ethical, reflexive subjects? Even if we ascribe authority to the researchers as being the ones we assume have a certain structural power, another picture emerges that speaks directly to these issues.

The subjects better affording the ethical reflexivity based in abstract, and therefore more ideal, reasoning seem in this case to be non-affected respondents with no particular relation to Parkinson’s disease—and neither, one can assume, to other diseases to which the same kind of research praxis is applicable (see Berglund & Lundin 2012, on how need and necessity feeds pragmatism). Paradoxically enough, this position leaves more room for dogmatism as well as for greater nuance. Something to be explored further is the question of whether this is also related to the fact that patients and researchers in this case are the ones closest to turning their ethical reflections into moral action and praxis (see Bommenel 2006), and therefore are in need of considering more complex parameters.

And surely there is a considerable difference between being faced with an abstract risk and an actual risk. It is worth noting that both patients and researchers seemed to be more vulnerable

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<sup>7</sup> Merriam Webster’s online dictionary, <<http://www.merriam-webster.com/dictionary/>>, s.v. ‘anthropocentric’, accessed 2 July 2012, July 2nd 2012 in 1: considering human beings as the most significant entity of the universe 2: interpreting or regarding the world in terms of human values and experiences.

in this process than were the non-affected respondents. Yet if the capital invested and jeopardized on the part of the researchers is their authority, beliefs, legitimacy, and the trust of others, it is primarily the patients' health and lives that depend on this judgement of risks and possibilities. So even if the transactions entwine the different currencies, it is questionable whether they are equal by exchange rate.

Subjects with a severe, biotechnologically targeted disease such as Parkinson's disease will choose a rather pragmatic view, then. I view this mainly as an expression of a strategy to cope with the threat of the disease; a way of dealing with survival being the ultimate focus. The way in which many of the patient participants avoided relating to the fetus as a life or an individual, and how some downplayed the possible trauma of the aborting parents, while others in effect announced that discussion on the topic superfluous, all supports the argument that the importance and actual effect (understood as both individual and societal) of the ethical reflexivity of the subject is highly dependent on the presence or absence of severe disease. This was further supported by several of the participants stating that they 'just care about a cure anyway'. Faced with an acute medical need, the relative luxury of ethical scepticism will in all likelihood be sacrificed.

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Paper II







## Cells in Suspense

### Unboxing the Negotiations of a Large-scale Cell Transplantation Trial

By Andr ea Wiszmeg

Throughout scientific work and research, many processes and procedures are made routine, mundane and then taken for granted. So are some underlying assumptions – not only about the state of the natural world, but about what its different actors are *supposed* or *expected* to be or work like. These assumptions are not only descriptive, but prescriptive. If we proceed from the notion that expectations and beliefs are written into our everyday practices and made opaque even to their practitioners, it becomes an urgent issue to find tools to better scrutinize and evaluate them. This is, I argue, a matter of ethics. *How* such assumptions are written into practices is perhaps as available as ever, in the instructions, documents and processes of evidence-based science. When some premises and practices are locked to each other, others are excluded. The aim of this article is to explore the dynamics of this process in a biomedical research practice, with regard to how it affects what are considered ethical issues and how they are handled.

Based on ethnographic fieldwork, I will investigate what happened when staff in a large-scale and multi-site cell transplantation trial in Parkinson's research had to scrutinize their procedures. I want to understand what subsequent negotiations needed to be done in order to progress; or, more specifically, what deliberations about perspectives, procedures and ethical issues of the project were required to see the trial through. The focus is on what the staff described as causing the major delays that they faced, and temporality is subsequently conceptualized as an important factor in the homogenization and reproducibility of science. I discuss how the necessary changes

and negotiations relate to the aims and standards presented by the rationale of evidence-based science, and the implications they have for research practice of future trials and for research ethics.

I argue that investigations such as this are crucial to better understand how ethical dilemmas are not primarily abstract deliberations addressed in policy documents, but embedded in everyday practice. I will also address the importance of ethnographic practices to this end.

In the following, the content and the conditions of the trial will be presented in context.

#### The Fetal Cell Transplantation Trial

Parkinson's disease is a neurological degenerative disease becoming more common with an ageing population. The most widely recognized symptoms are tremor and rigidity of limbs, but often also include dementia and depression. Researchers have been able to pin down the major cause of the disease to damage in a specific brain region and subsequent loss of dopamine production. Dopamine is a neurotransmitter that, among other things, regulates body movement and plays a major role in mood regulation. Even if the cause of the disease is known, the treatment of Parkinson patients still today mainly consists of relieving symptoms. Many biomedical research initiatives and resources are directed at finding ways to treat the cause of Parkinson's disease directly, and ultimately, it is hoped, to be able to cure the disease. One of these is the TransEuro study (<http://www.TransEuro.org.uk>), which in the first large-scale trial will transplant fetal neural cells to the brains of patients, with

the aim of making their brains start producing dopamine again. This trial is the empirical case for this article.

Being the first large-scale cell transplantation endeavour, pose some formerly unseen challenges of coordination and standardization. These changes are required in order to produce the big data sets needed to legitimize the results as “evidence-based science”,<sup>1</sup> a concept and a standard that has, it can be argued, more or less grown to define “good” medical basic research, as well as its implementation in health care. An infrastructure allowing not only the procedures at hand to be done, but in the long haul with stem cells from leftover IVF<sup>2</sup> embryos or further along, reversed skin cells, needs to be established and up and running. These new circumstances require clear guidelines, reproducibility and better outcome predictability. Such implementation needs adaptations to new standards and to other trial sites, which is a contrast to earlier work done on a small scale and locally. All of a sudden – when forced into a new narrow, but large-scale, framework – the cells seem to start to behave in an unruly fashion.

The trial process includes the harvest of cells from aborted embryos, their preparation and preservation and the subsequent implantation of the fetal cells, in the form of a liquid cell suspension, into the brains of a number of affected individuals volunteering as research subjects. Lund University has from the start been at the forefront of cell transplantation research and performed very early fetal cell transplantations back in 1987. Proof of principle was then established that fetal neural cells can connect to their surrounding tissue and start producing

dopamine, once transplanted to a host brain of a rat or a human. This trial aims at developing a better template for being able to move on to using e.g. stem cells from leftover IVF, with the final (but still distant) aim of curing Parkinson’s disease. As such, the fetal material derived from abortions used in the trial is not regarded as a final solution. Four aborted embryos are required for one transplantation in a human, but the medical abortions which are so commonly performed in the home of the patient nowadays have created a shortage of donated embryos available for research. In addition, the sometimes failing logistics between abortion clinics and research facilities jeopardizes the already scarce material. The situation is not helped by that fact that the material, since it is developed “naturally”, is not homogeneous and therefore not reliable in terms of quality and usefulness. It has not formerly been relevant to prepare for moving on to human embryonic stem cell lines for transplantation, mainly due to risks of tumour growth. But with developments in the field and the recent breakthroughs in autogenous skin cell reversal, a new flame of hope in cell transplantation has been lit.

### Methods and Materials

Being part of an interdisciplinary endeavour where my project is co-financed by the Medical Faculty of Lund University, I was granted access to planning group meetings and to general information on the project. Based on their own interest and availability, I also made contact with some staff for interviews and observations, for example, in the laboratory. When the local planning group of TransEuro met at BMC or the research hospital in Lund, I often attended

and made observations and notes regarding perceived progress, obstacles and measures needed to be taken. The nine meetings that I attended took place during spring 2013 and onward throughout 2015. BMC just as often rather functioned as a virtual node of reference to or from e.g. legal and practice documents, notes from meetings, e-mails and phone calls. Documents used as source material could be, for example, SOP (standard operating procedure) and GMP (good manufacturing practice) protocols, which are supposed to inform and guide the minutiae of laboratory processes, and ensure that cleanliness and reproducibility are guaranteed. These are the kinds of heterogeneous sources I used to construct my material. The story that I let my empirical material tell here is centred on junior researcher Emma,<sup>3</sup> who was my main field contact whom I usually e-mailed, called or met when I wanted something confirmed, explained or problematized, or just needed access to the BMC building or other sites relevant for my research. She was truly invaluable for my research.

In the following I will, with the help of the materials described above, trace how and why occasions perceived by the planning group and by my main contact as passive and uneventful, could rather be – as argued by Billy Ehn and Orvar Löfgren (2010) – seen as productive and creative within, and of, the process. I have gone through my notes and e-mails in chronological order and recreated the course of events as they were described to me. By combining the recreated course of events I have also made a relational analysis of sorts, of the different documents (which will be addressed in more detail in the empirical and

analytical parts of this article) with regard to how they facilitate the creation of the cell suspension and try and make it mobile, by managing the delay in the course of events. For my purposes in this text, they are not so much analysed with respect to their detailed textual contents, but rather for the processes they enabled, disabled or in any way regulated; i.e. how they were put to work as actors. The analysis will be made of the materials as a combined source of information.

After first backtracking and describing the events that occurred while the staff were waiting to get started with the trial, I will investigate what kind of negotiations of procedures and rationales were taking place. I will use the concept of black boxing and unboxing (as will be developed further below) to understand the role of the events. I will return to my field material to discuss where certain problems arose and how and where their subsequent solution was sought by the different staff involved. In order to make sense of how different events, actions, actors and problems were connected to each other and to questions of knowledge, scientific standards, ethics, evidence and mobility, I started to map out how different problems were dealt with in different ways.

My diverse research practice taps into a long tradition of creating ethnographic material of a *bricolage* kind, which combines and compares diverse materials to each other so that a new picture will emerge (Ehn & Löfgren 2011:203f). It is a multi-methodological inquiry of sorts. Such an approach has advantages, I argue, when researching knowledge-producing practices, since they are in themselves highly heterogeneous in both the forms of information

used for constructing and for expressing, legitimizing and communicating knowledge.<sup>4</sup> The context of my research also lends itself well to the kind of shorter, sometimes close-to-home fieldwork reality of applied cultural analysis, often producing a compositional ethnography (O'Dell & Willim 2015).

The mixed material was constructed through what can also, to some extent, be called a mobile ethnography (Marcus 1995:96) done over the course of about three years between late 2012 and late 2015. I mainly follow the relation between the time, delay, negotiation and progress of the project, in order to create my ethnography and my arguments. The construction of the cell suspension and the framework needed to produce and maintain it took place in meeting rooms, in policy and practice documents, in frustrated discourse and in the subsequent negotiations taking place between sites. In a sense I have been “following things” (1995:106), the things in this case being the delays in relation to the creation of the cell suspension and its maintaining networks.<sup>5</sup> I have let the staff, and the documents they produce, explain to me what the sources of delay are, where they occur, what the effects of this delay may be, how it is connected to other processes and how this connectedness may in turn cause more delay. The delay of course had different causes, and these causes led to suggestions as to how they could be overcome to prevent further delays and move on. Following the chain of delays led me to the vital points of negotiation of new structures and procedures that the project underwent.

Having defined my method and materials, I will now move on to the perspectives I

will use for analysis. The aforementioned concept of unboxing helps direct attention towards the production of the fetal cell suspension and the negotiation of the network and structure needed to make it homogeneous, reproducible and mobile in a multi-site trial.

### **Production, Homogenization and Mobilization**

The cell suspension carries an inherent value of vitality (Rose 2006:7), or “force of life”, since it has the ability to repair the brain and restore some functions. The vitality can be transferred to the human brain and repair some of its functions. This value is the main reason for taking on this challenging research endeavour. The value of vitality is, it can be argued, a kind of potentiality. This inherent potential points to expectations and promises of the future but also to the ability of humans to control and manipulate the potentiality in the desired direction. This gap between present and future and the imagined evolution in between also grants mythical and magical qualities to this potentiality (Taussig, Hoyer & Helmreich 2013:4ff).

For the cells to finally fulfil their potentiality, they need to be made mobile in order to reach the patients in the trial, and this requires getting a certain infrastructure in place between sites of supply, production and research. Logistics, timetables, measurements and protocols must be standardized, formerly having been a local issue only. The construction of this infrastructure tends to get messy the more sites that are involved simultaneously, and delays and subsequent waits occur. It is the role of time and delays that I will now set out to investi-

gate in the “mangle of practice” (Pickering 1993) as it occurs in the project. In order to better understand how the homogenization and mobilization of both procedure and product are enabled, the concepts of black boxing and unboxing can help us visualize and rationalize the negotiations and unveiling of former opaque practices and points of departure that the staff have to go through.

When procedures are established and routinized so that a process runs smoothly and a technology or science is successful, its workings are “black boxed”<sup>6</sup> (Latour 1999:183). For instance, as I press the keys on my laptop writing this, I do not (usually) spend any time wondering about the microprocessors and the wiring enabling the impact of my fingers to be turned into signs on a screen through software. I doubt that I would even if I were a computer scientist or and engineer, and not a scholar of the cultural sciences. When the results that come out of a research practice or method make sense and are coherent, there is no focus on internal complexities (1999:304), whether you are intimate with the workings or, like me, in the example with the laptop, are oblivious. It is only when some things break or stop working, or when results are inconsistent, that it is necessary to open the box (1999:184f). If something inside the box breaks, it needs to be taken apart by someone who understands the relation between the parts and can identify what component or connection is faulty. If, let’s say, the products of a biochemical procedure start varying in content or concentration, someone with knowledge of the biological or chemical material processed, as well as of the components of the system and their re-

lation, will have to make a judgement and take action. Once action is taken so that everything works as expected and parts and operators or staff are once again aligned (1999:184), the process will once again become routinized and black boxed. The “black box” status is what is always striven for, and a default setting of sorts. When a process is black boxed, its separate parts will behave and be perceived as one. They are acting together as an assemblage in which they can be hard to distinguish from one another. It is important to remember that this goes for viewpoints, analyses, positions, philosophies, concepts, politics and ethics just as much as for parts, components, materials, elements, people, animals, etc.

Beginning to unbox something is often done on the basis of something not working, and it is the part suspected of failing that is first recognized as a separate and discrete part again. If it turns out not to be faulty, or that exchanging or repairing it did not fix the problem, a trial-and-error process will begin. This process is the essence of unboxing. In the case of the start-up of the cell transplantation trial, the “breaking down of machinery” is to some extent foreseen. The participating sites know that they will eventually need to unbox some or many of their formerly locally taken-for-granted routines in order to be able to cooperate; both on a practical and on a more abstract level. What this can mean will be demonstrated in the empirical material and analysis to follow below. But if black boxing is the almost unconscious process of making something an invisible routine by habit, how does one go about unboxing the “forgotten” and opaque? To unbox some-

thing or to make what is described by Latour as a “reversed black boxing” (1999:184) takes a whole lot more work and effort than the opposite.

In larger cooperative endeavours where abstract goals and concepts and not “only” concrete matter need to be manipulated in order to reach the level of smooth functionality that the new subsequent black boxing offers, a lot of negotiation and mediation has to be done. Attentive readers will probably themselves spot many of these instances in the story of the trial, but I will now join you and the researchers of the trial in unboxing this story.

#### **Preparing a Large-scale Trial – Dealing in Delay**

Prior laboratory results on which the participating research sites wished to base the trial seemed inconsistent between the sites. Guidelines, practices and ultimately timetables, partly, therefore needed to be revised and the project was facing an increasingly serious delay. A lot of practices and points of departures were questioned, rethought and rejected during these times, but maybe just as many new ones would ultimately need to be established and consolidated in order to move on. The researchers needed to go through an uncovering of formerly opaque practices and processes in order to make such change happen.

Since December 2012 I had been in contact with junior researcher Emma, who happily agreed to help me gain access to the sites that I would need and to guide me through all the steps of the process. In order to prepare the staff for when the transplantations of the medical trials were eventually to be carried out, a number of dress re-

hearsals (called “dry runs”) had to be done. Finally, after seven months of anxious and frustrating waiting for me, the staff and the patients, these started to be prepared for. I had been informed that the dry runs were to start in early February 2013, and that I would be updated as soon as any information relevant to me was available. I got some preliminary dates for planned dry runs throughout February and was very much looking forward to starting my fieldwork. However, as February passed, there was negative information week after week that they had not got the right amount of fetal material in order to be able to perform any dry runs. I received weekly e-mails with an aura of resignation from Emma, stating that there would be no dry run this week either. Transplantations to rats could, however, still be done with the available amount of fetal material.

At this point, I started to realize that these delays could be said to be quite normal in such a large cooperative medical trial. All the coordination and common standardization that needed to be done, in combination with reliance on a delicate and obviously scarce material such as fetal tissue, paved the way for delays. Recurring practice in order to get into routines for performing the procedures was much needed by all involved parties in such a big project. Sites and procedures needed to be coordinated in order for a common goal and a common understanding of it to be imagined and created. So far, there was consensus that the participating sites would produce a cell suspension for transplantation in a common fashion, do all transplantations the same way and have a shared follow-up procedure within a certain time frame. At this

point, the local procedures were in a sense black boxed from each other and from everyone at their local laboratory due to routine, and even more so for the staff at the other trial sites.

### **Achieving Stability, Reproducibility and Mobility**

Throughout the process and later during the spring of 2013, participating in the meetings of the project's local planning group gave me even further insight into and information on how this coordination was performed. At a meeting in late April, points of concern were a number of legal and procedural documents that needed to be homogenized and standardized between the researcher groups in the participating countries. One such critical document was the ethical permit for donation of fetal tissue and the informed consent sheet that needs to accompany each donation. There seemed to be differences regarding how the information on the consent sheets was to be formulated, depending on whether the tissue was to be used for experimental or clinical (as in this case, transplantation) purposes, and general differences between the countries. Further, if the tissue is to be used clinically for transplantations, the UK legislation demands total traceability of the tissue. This circumstance presented another issue for the Lund researchers, now having to first establish a tagging system for the tissue, and second, to establish a biobank to store the traceable tissue. Traceability is needed to make sure that any possible infection in the patient caused by the transplant – however minimal the risk of this happening – can be traced to the right fetal source. Otherwise it cannot be considered

safe enough to transplant. If this is not achieved, the cell suspension cannot become mobile, neither over research sites nor between donor and receiving patient. By making the tissue and the recipient anonymous but traceable by allocating the corresponding numbers or codes, a tagging system is created. The key to the code system, containing the “real” identities, is held by one trusted person and is protected by strict secrecy. This procedure may be familiar to the ethnographer anonymizing interviews.

Since the researchers – because of the constant shortage of fetal tissue – wanted to be able to use all available tissue for both experimental and clinical purposes, this posed a practical problem for them. How were they going to design the use-of-tissue ethical permits in order to make most use of the total amount of tissue, whether it is earmarked for experimental or clinical use? It was suggested that including a pre-clinical stage in the project plan could help overcome this issue. It was suggested that the constant overarching shortage of fetal tissue should be targeted by allowing not only gynaecologists but also midwives to ask aborting women to donate their embryos. They also planned to present the project and the procedures to gynaecologists in clinical facility in a neighbouring city, in the hope of obtaining fetal tissue from them too. The researching team hoped that this would generate more fetal tissue all in all. The researchers delegated responsibilities for different tasks to be solved or at least targeted before their next meeting. The practical circumstances of access to and the state of the right locations and equipment were to be taken care of by a surgeon and one of the laboratory staff – my contact

Emma. The information and format of the ethical permits and finding a model for a tagging system for the fetal tissue, was to be taken care of by the official project leader.

It was stated by Emma and others in the laboratory staff that they needed to do at least three dry runs before Midsummer and one in early September, in order to be properly prepared for the transplantations planned to September. This was because they needed to practice the procedure of washing the fetal cells of all unnecessary tissue and other kinds of cells. The practice of washing could be done on untagged tissue, which would save them some time considering completing the tagging system and the special permits and consent sheets needed for it. They all agreed that the bottleneck for progress seemed to be the question of access to sites and equipment, and the traceability of tissue. One of the reasons why access to sites was a bottleneck was that the room in which the dry runs were going to be made need to be a strict clean-room and free from polluting particles such as microbes. This too, would grant the cell suspension mobility from laboratory to patient. First, there was a problem in finding a room that can be guaranteed to have this status for such a long time, and that it would be available when needed. There seemed to be competition over such sites with other research projects. Second, guidelines and standards between the participating countries needed to be tuned and homogenized, and in this there seemed to be some ambiguities.

To get this in place was of the utmost importance to be able to make a standardized and reproducible cell suspension. The

planning group agreed that what the laboratory personnel would need to look to was that there would be access to a controlled environment although not needed to be sterile, and that there was an airlock in this room. This was considered good enough for the dry runs. The researchers and the laboratory personnel referred to concepts such as good manufacturing practice (GMP) as being an index for the standard of the clean-room, and standard operation protocols (SOP's) as the protocols regulating the procedures of cell washing and preparation. Both can be said to be crucial for creating a homogeneous product in the form of the cell suspension. It was concluded during the meeting that the laboratory personnel and junior researchers (such as Emma) would be taking care of adapting and homogenizing these documents, such as the SOP's, guiding the procedures of handling the cells.

### **Fetal Demand**

In early May 2013 Emma and other laboratory personnel observed that three embryos were not enough for the dry runs, and at one of the recurring planning group meetings, a considerable amount of time was allocated to discussing this specific problem. Four embryos were needed, which made it even more difficult to reach and complete the dry runs, since there is a constant shortage of embryos throughout Europe. The demand for the vital force embedded in the embryos is larger than the supply, which hinders not only the production of cell suspension, but of the specific and homogeneous cell suspension needed. Even if the staff in Lund had formal access to supply from at least three locations, they couldn't seem to meet



the demands of using four embryos.

The traceability issues remained, and project management had nothing to report on the progress of this. However, they suggested that they could copy the procedures of tagging insulin-producing cells, from another facility. Doing this would save time and avoid further negotiation and unboxing of rationales behind the system, which could possibly have been needed if a system were to be first invented and then agreed upon.

The group of researchers was now hoping for fetal tissue to use in the dry runs to arrive from the UK in the middle of June. Related to this, they discussed how the differences in fetal tissue collection procedures within this project deviated from normal procedure, and that these differences needed to be communicated to their contact at the abortion clinic in the nearby city from which they hoped to collect more tissue. The testing of the donating women for sexually transmitted, and other, diseases was also a question of negotiation. While the other participating Swedish location tested for a variety of infections, in Lund they tested only women who were considered to belong to risk groups for two of them. Here, a consensus between researching sites had to be reached as well, in order for the cell suspension to be made mobile. If consensus was not reached about the level of safety (or risk) concerning infections the cell suspension, it could not travel between sites without worrying the staff in some of them. In a sense, this negotiation was a matter of instilling trust not only in the patients to be transplanted, but also between the researching sites. Someone would eventually have to adapt to the other's rou-

tines, but so far it was not clear who would.

The concept, or the idea, of the cell suspension had to be homogenized and made geographically mobile in order to be discussed, understood and reproducible between the research sites. In the same way, it also had to be homogenized as a concrete, material and specific object with specific properties, to be made mobile between organisms and fit for transplantation in the human brain.

The participants at the meeting were informed by project management that the other participating Swedish research site had also decided to expand its fetal tissue collection from one to three days a week, which was the number of days Lund already had. The meeting ended with Emma bringing up for discussion the gravity of not being able to access the cleanrooms soon enough. Was it possible for them at least to perform dry runs out of cleanroom so that they could get started? She argued, without success, that they needed the practice in order to be able to perform correctly when the actual trial was to be done.

### **Fetal Supply**

In order to best manage the shortage of embryos and to get most material available from the abortion clinic in the nearby city, a meeting with a midwife there was arranged. I went there together with Emma, who was to hand over protocols describing the new routines needed for handling the embryos for dry runs and transplantations. She was also going to supply them with new pots and a different hibernation fluid.<sup>7</sup> Formerly, whatever plastic pots were available in the laboratory had been used, the lid on it kept in place with tape, and the pot put on ice.

But now, moving from small-scale experimental research to a large-scale trial involving human patients, a more standardized procedure was required. The temperature needed to be monitored and only sterile equipment was to be used. It did not seem certain that this new procedure would actually make a difference to the state and quality of the embryo as material, but when material is to be transplanted into a human being, there can be no risk of contamination, no matter how minimal. All measures taken were to serve the end of achieving a reproducible cell suspension, mobile between the organism of the embryo and the organism of the patient.

When entering the midwife's office, we were asked whether a recently aborted embryo in their fridge would be of use to us. The aborting woman just gave her consent for using it in research. Emma could immediately tell that it was way too old and developed to be of use to us. The TransEuro trials require fetal material from embryos six to nine weeks old. This age span is where the neuronal cells of the fetal brain are at just the right pre-stage of development needed for transplantation. We found out that in their normal schedule of abortions they usually obtained the embryos of interest to TransEuro on Fridays. This was unfortunate, since the transplantations within the trial were to be made those weekdays, which made Friday the one day impossible for the researchers to receive material. Emma seemed confident that adjustments of the schedule could be made to better fit the trial, provided this did not impact the women's decision to donate or not. The midwife told us that with the procedures they had at that time, no pot for col-

lecting the passing from the abortion was used in such early stages of fetal development as we required. This, however, seemed like something they could easily incorporate in their practice. Emma handed over the protocols and informed the midwife that they needed to use sterile cloths and disposable forceps.<sup>8</sup> Emma and the nurse promised to look to supply the abortion clinic with these things. Emma also gave instructions to the midwife on how the new hibernation fluid was to be used. They agreed that Emma would inform the midwife when a dry run week was to be expected, so that they could prepare at the clinic. The shared responsibility for implementing the new guidelines and practices across the sites made the creation of a unified and reproducible cell suspension simultaneously messier and more necessary. An unboxing of procedures had been done, and establishment of new ones awaited. The more parties involved, the more work.

Later, back at BMC, Emma told me that access to the cleanroom was still the major issue of delay. This was felt to be extremely frustrating. No one seemed to know what had happened, or what would happen. Here, the cleanroom itself was in a sense a black box, into the workings of which not many seemed to be allowed to peer. The lack of a cleanroom went on hindering the staff from proper practising of the routines. The practice was in this case not hindered by, say, financial issues or by lack of knowledge but by lack of access to a specific site. The question of the cleanroom was an interesting example of how issues of place and materiality were so highly interconnected with issues of knowledge and evidence. Cleaning procedures for normal working

laboratories still have high standards to prevent pollution. However, the need for a legitimate cleanroom was based on the need to be able to be trusted to produce evidence-based science, and subsequently to be allowed to take part in the large-scale trials and thus enable the mobility of the cell suspension. Gaining access to a cleanroom was not an end in itself, but aimed at the production of a homogenized fetal cell suspension accepted for travelling on to a patient and at gaining the legitimacy of evidence-based science.

Earlier during that year, problems with very varying results in cell survival were found across some participating sites. This caused a lot of confusion and worries among staff and management, but was finally overcome when Emma travelled to make observations in the laboratory of the site with the largest deviations. Not until she witnessed their procedures live could it be detected that they treated the cells somewhat differently. After this, an even more specific SOP (standard operating procedure) was created to use across the involved cell laboratories. It was also discovered that there were differences in the measurement and calculation of the innervation (nerve growth) in rat brains across some sites, and this too was handled by establishing a new standard for all. These measures aimed at establishing a homogeneous cell suspension for transplantation and at a way of making it mobile as a conceptual object of knowledge, across the sites. As Jonas Frykman (1990) pointed out (concerning the need to develop and establish better field work methods for capturing and understanding practices and practical skills), it is difficult to understand and even

more so, to master a technique only by reading about it or having it described to you. It is not until you try, practise and embed the knowledge into your own body that you will truly have learned (1990:50f; 60).

Finally, in October 2015, the laboratory had undergone major renovations and a dedicated cleanroom was established. The shortage of fetal material did not seem to have been solved, even though the procedures and logistics between abortion clinics and the cell laboratory had got better. However, it was a system based on former personal contacts and oral agreements, rather than on routinized or formalized procedures. When staff changed or went on sick leave at the abortion clinic, there were recurrent hold-ups in the supply. It seemed to be a fragile system. Up until the autumn of 2015, not all dry runs planned and needed had been performed. Some had, but not enough to get reliable data. Just during October, they had been cancelled three weeks in a row. Another later occurring cause of delay was the clearance of the permit for the procurement and use of tissue, which still needed to be issued by the Health and Social Care Inspectorate (HSCI).<sup>9</sup> This was the last legal hurdle for the project to overcome in order to be able to transplant. On top of the problem with the deteriorating state of health of the waiting patients as time passed, HSCI being dilatory concerning the permit was another reason for concern since the funding would run out in December 2015. The planning group perceived the chances of Lund getting added funding less probable if they could not show any transplanted patients before then. Fortunately, the project was nevertheless prolonged, and as of February 2016 was

hoping for their first transplantations to patients to be performed during that same month.

### Negotiating Time

As it seemed, time passing and “nothing happening” as it was experienced by the involved researchers and other staff waiting for access, information, protocols, signatures, equipment etc., actually contained a lot of productive components. Following the delays of the trial proved to be a crucial move for understanding the moulding of the fetal cell suspension, the common understanding of it and the paths to its mobility. The black box may be a spatial metaphor, but it certainly also has temporal dimensions in this case. The opaqueness of its surface in a sense makes the box itself invisible. The lack of information was rather experienced as a frustrated waiting and eventless time passing, rather than the non-transparency of a box.

The biomedical trial I have been observing is both large-scale and aiming to develop a future research model on cell transplantation with hESC. These circumstances make it, I argue, a case where future generations of trials are concerned. The trial has what Karin Knorr-Cetina calls genealogical time (1999:186ff), since it “matches collective mechanisms with long-term thinking” (1999:188) in its negotiation of procedures and guidelines. Opening the box, reassembling its contents and their relations, enables a new knowledge-producing machine. In order to make this machine endure over time and future trial generations, the scientific rationale behind the procedures must be so firmly built into it that no there is no need again to open the

black box in which it lies. In reality of course, such strong locks can never be made. The cell suspension and the new knowledge produced around it was created by reaffirming old knowledge (Walford 2013:30f), such as data on expected cell survival and innervation. This was because the cell suspension to be created already has a script to follow. There is a “right” cell suspension, and all other variations are wrong. If this were the first cell suspension around which all to follow would be moulded, it would allow and presuppose an openness to uncertainty, past as well as present and future (ibid.; Pickering 1993:579), which is not the case now.

Managing manuals and guidelines seemed first of all to be a matter of adjusting either material procedures or circumstances to what had been written; as in the case of adding pots for the fetal passings at the abortion clinic at certain dates, or the other way around, adapting what had been written to the concrete materiality and adjusting what had been written in one location or on one level to what had been written on another, which we have seen in the cases of local guidelines and permits being homogenized. The adjustments were a way of coordinating the process with its involved actors in order to be able to reach a common product for transplantation. Some of these adjustments, such as how the ethical permits relate or dissociate women to embryo and patient, were a result of unboxing the process. As such, they acted to create discrete objects in specific categories. The subsequent new black boxing that inevitably needs to follow upon the unboxing of the former order at some point will act to establish the categories as rigid and “truth-

ful”, as an effect of the new opaque and black boxed process. Such categories make simpler the process of creating laboratory procedures, medical trials and thus, evidence-based science. The documents of course have a great influence on the end result of the cell suspension and the trial as a whole. They are an important part of the network of making it all work – or part of a knowledge-producing apparatus (Barad 2007:148, 176).

The preparations for the trial can be said to have been aiming at maintaining the vitality of the embryo throughout its transformations into a mobile cell suspension and a subsequent treatment. A “snapshot” was, as mentioned earlier, made out of a biological process with technological aid. This was required for fitting this object into the evidence-based framework of knowledge required for the trial. Still, it was a simultaneous moulding of a new relational infrastructure and of the travelling object: the cell suspension. The trial can be said to aim for creation of sameness rather than difference, since the aim is homogeneous and reproducible procedures, as well as a cell suspension made to these same standards. The delays, the time passing and the subsequent frustrating wait were mainly a product of trying to create sameness out of a resisting nature insisting on being different. So, if it is the “differences that make a difference that matter” (Barad 2007:36, 72), it is here more precisely a question of the *material differences which tirelessly resist being made the same*. In evidence-based science, quite contradictorily, the creation of sameness could be said to be aiming at proving an even more *specific difference*; the difference *this* specific treatment does in

*that* specific situation; a tailored vitality. Charis Thompson writes, concerning in vitro fertilization practices, that it is the spatial and also temporal separation between the donor, the created object (the fertilized and implanted egg) and the patient that creates a successful treatment and practice (Thompson 2005:100ff). This is true also for the cell suspension I studied. However, evidence-based science takes it further, by reducing what has already been enacted into discrete objects and started to act independently, to a controllable behaviour pattern that, by producing *sameness*, produces the specific sought-after *difference* that the trial wants to prove. One of the reasons why the staff needed to unbox their procedures was that a working and intact black box in biomedicine requires homogeneity and reproducibility. These are two characteristics that do not naturally apply to the fetal material.

Delay and wait can therefore also be seen as consequences of the priority of creating *general sameness* or reproducibility within the trial, in order to produce, identify and prove as a result the *specific difference* that is the effectiveness of the specific vital force. This is a force that can be essentialized and removed intact from its original context: the aborting woman and the embryo. Thompson’s perspective on temporality can help us better understand that matter not only matters in space but also in *time*, when we consider how the laboratory-working researchers in the trial tried to backtrack for errors that produced failures and how this was a way of managing past and “lost” time into the future (2005:105) as part of producing the cell suspension. The reaffirmation of old knowledge (Wal-

ford 2013:30f) was used to create a standardized object. In a way, the researchers can be said to have tried to reverse or transpose time.

Time and delay helped visualize the crucial negotiation points of the project, and made visible to the staff what procedures and premises had to be unboxed and what could maybe, in later phases of the process, be routinized and put in another opaque black box. Since premises are not neutral however simple and small they may seem, we now need to consider what implications the black boxing process may have for ethics.

### **Ethics in Practice**

How did the negotiations of practices in and of the trial affect what were considered ethical issues and how they were handled? What unconscious premises were black boxed, and which ones had to be unboxed in order for the trial to progress?

The fact that there was a constant shortage of embryos did not stand unaffected by other problem clusters in the project. For instance, in order to find a solution to the shortage (a problem in itself unsolvable by ethics regulation) management tried to adopt or to design a tissue tagging system and a biobank, which would allow the use of more of the already available tissue. The system had to fulfil the ethical demands on both preserved integrity of donors and the safety of recipients. They hoped to be able to do this by adding a pre-clinical stage to the trial, with less rigid regulations on traceability. This way, more tissue could be available for making cell suspension to implant to rats. When the transplantations to humans are to begin, the clinical stage regu-

lations must be put to use again. A tagging system is always required when using biological material in clinical trials to make the tissue traceable in the event of contamination or disease. This helps create chains of reference and makes back-tracking easier, and is in itself a requirement of doing science (Latour 1999:25–79). This chain of reference allows not only for abstract knowledge production of the fetal cell suspension and its relations, but also for putting a matter-creating apparatus (Barad 2007:148, 176) into action, producing e.g. documents and biological samples and a filing system.

Trying to adapt abortion schedules and add pots to collect fetal passings in the abortion clinic was considered a safe way of trying to gain more material without having to enter ethical deliberations, as was necessary with the adoption of tagging systems, biobanks and adding SOP's (standard operating procedures) for a pre-clinical stage as described above. The manipulation of matter described above did not seem to be directly considered by the staff as being connected to ethics, in the way that manipulation of documents and permits seemed to be. However, the local procedures still install a new order, which comes with premises. Here, the premise was that other facilities' routines can be remade and unboxing "outsourced", so that unboxing and negotiation in one's own project could be avoided – as long as no pressure is put on the aborting women.

As we have seen, both ethical and scientific considerations meant having to open up the black box for relational reconfigurations, which meant more hard multi-sited work from the staff: for instance, having to

remake and then homogenize permits, or needing to travel to see and understand how practically different but theoretically equal procedures at other sites could produce inconsistencies between them. Taken at surface value, it looks as if connection and reference to the making of the fetal cell suspension and of evidence by pursuing more fetal material ended here. This holds true if we only consider the efforts to obtain greater volumes. However, it was just as much a matter of selecting the right embryos, since their size and age were crucial factors in making the cell suspension an accepted traveller, with the right qualities, to the brain of a patient.

The documents that seemed to cause most problems and subsequent delay were the national ethical permits for the trial itself, for the donation of fetal tissue, and the tissue permit. The adaptation of the SOP's and other protocols of more practical and manual-like character was handled by laboratory personnel and junior researchers. This, for two reasons, made this process easier and faster. Firstly, the junior researchers and laboratory staff did not have the same load of paperwork needing to be taken care of as did more senior researchers in managerial positions. Secondly, this adaptation was done in dialogue with an actual material research environment, which the document was mainly produced to describe and to some extent manipulate. The adaptation was also done in relation to the other involved research facilities and their procedures, in order to be able to create evidence-based science (as discussed by e.g. Kruse 2006 and by Berner & Kruse *et al.* 2013) and to progress in the trial.

Problems that were handled by manage-

ment in the first instance as administrative ones were issues such as responsibility for testing the fetal tissue for sexually transmitted and other diseases in an acceptable and standardized way; which of the protocols were to be adapted to regulations and homogenized (which is in practice done by laboratory staff), and how randomization of human research subjects – the participating patients – was to be done. On a closer look, however, these problems inevitably connected to issues of evidence and knowledge. This was because since they all dealt with issues of how knowledge can be reached in a legitimate way and how all surrounding systems needed to be adapted to support such credible knowledge production, thus reproducing a homogeneous fetal cell suspension, a certain research paradigm and a worldview based on the assumption that certain mechanisms and causations are valid even outside the specific paradigm. This is also a good example of when issues of knowledge connect to ethical issues. For instance, deciding which of the donating women is regarded as belonging to a risk group, or how randomization of patients is best arranged in order for them to still be granted anonymization and unaffected health care can very well be regarded as ethical decisions. In a way, these are examples of instances where invisible premises are being black boxed into the apparatus of evidence-based science.

Problems causing delay seemed to occur most often concerning issues of either access or supply. In some occasions the problems arose directly on a prescriptive and almost metaphysical level, as in the cases of e.g. homogenizing protocols and ethical permits. Decision making in specific issues,

planning ahead both on local level and in communication with the other sites and with ethics boards, required managerial and administrative action. Most often these actions had direct consequences for questions of knowledge and evidence. Curiously enough, they did not as often have a direct effect upon the more practical issues of supply of fetal material or access to sites. These issues were more often targeted directly by the staff most affected by and in closest contact with the situation. The problems handled by staff in e.g. the cell laboratory almost exclusively had to do with practicalities of solid, material infrastructure not working to make the healing potential of the fetal cell travel as expected. The problems handled by management had more to do with the judicial and research-ethics problems of making the cell suspension mobile. However, both had their roots in issues of reproducibility and mobility and subsequently a legitimate evidence-based trial with intact notions of ethical conduct. And they both, I argue, had a comparable amount of influence over the areas they related to.

As has been addressed earlier, however, once negotiation is done, procedures and material stabilized and problems forgotten, it will all be routinized and mundane, and eventually black boxed again. Premises will be written into the procedures themselves and made invisible. Not until an unboxing must be done for some reason will some ethical issues need to be revisited. It is therefore of great importance to try to be aware of and accountable for what one locks inside the box. However, this is easier said than done. As has been discussed over time and at length by ethnologists (and

medical anthropologists), there is a constant need to investigate (and revisit) the everyday practice of medicine from a cultural-analytic perspective in order to get at how the ethical dilemmas are most often embedded in their contexts and mundane actions (see e.g. Fioretos, Hansson & Nilsson 2013; Lundin 2004; Lundin (ed.) 2007). Even if these points have mainly been made in relation to health care and doctor-patient relations (see e.g. Hansson (ed.) 2007; Skott, Dellenborg, Lepp and Nässén 2013), I argue that they are just as applicable to basic research and medical science as such. It is important to map out the black boxed assumptions of what research in medicine *can* and *should* do, even in the absence of, and prior to meeting with, a patient of flesh and blood. Only then can also the most routinized processes be unboxed and opened to scrutiny. The close-to-practice and context-aware “everyday ethics” perspective, as suggested by Ingrid Fioretos, Kristofer Hansson and Gabriella Nilsson (2013), is just as relevant here.

### **Ethics in Suspense**

Entering philosophical (and ethical) deliberations complicates things. It opens up for the possibilities of a topic to become heatedly debated and consensus impossible (or at least much harder) to reach. If a topic is instead discussed and unboxed mainly as practical matters, such debates can more easily be avoided, consensus kept and progress of process continued at a steady and faster pace. The rationale of avoiding discussions of knowledge and of being is the gain of a maintained consensus and a less fragmented staff opinion-wise, as well as an ultimately faster trajectory towards a ho-



mogeneous cell suspension made to travel within a legitimate evidence-based trial. I cannot argue that this process is in any way exclusive for biomedical or life sciences research, but one can see how it effectively helped to create and distribute the value that the cell suspension is attributed due to its vitality (Rose 2006).

It is important to point out that the value of the cell suspension will not be available on an open market, since it is not patentable due to European Union legislation on commercialization of materials of human origin.<sup>10</sup> Neither can the production or distribution of the cell suspension be large-scale, because of the scarcity of the fetal material. Still, it can be considered a prototype for future embryonic stem cell therapies, which may not be patentable either, but still tentatively possible to apply on a large scale since they can be more easily homogenized and reproduced. The investment in the trial itself cannot, due to the given limits of the fetal material, yield any gains or advancements for this specific form of therapy. However it is arguably still important for them to move forward within the trial, so that it can eventually “pay off” in the form of development of embryonic stem cell trials and hopefully future therapies.

The tendency seemed to be to prefer and suggest easily incorporated practical solutions in answer to raise ethical or philosophical topics, rather than extensive discussion of them. The possible consequences of such a pragmatic strategy in my case study is not easily observed or summarized. There certainly is an ethical awareness, adherence to ethical guidelines and accordingly a plan of action that the group agrees

on; not much discussion seemed to be needed to sort out acceptable from non-acceptable actions when sensitive issues appear. All discussions, however, were based on the assumption that the transplantations *would* be carried out.

What is made to come into being to endure and the knowledge of this being is in itself an ethical issue. Science as such has great influence over, and therefore great responsibility for, what is created and acknowledged as being and what ought to be. The ethical aspects in need of consideration in the case trial were most often integrated into questions of knowledge, evidence and meeting goals. It was most often also embedded in the negotiations of practices. Ultimately, the aim was to be able to continue the trials, even if large changes were needed to make it ethically acceptable to donors, patients, the public, their peers, themselves and to ethical boards. Since the researchers needed to lock the opened black box as fast as possible in order to continue, some ethical perspectives would be approved while some would be left out. Keeping both the cells and staff in suspense also enabled practical solutions to ethically delicate matters, which would otherwise have led to quandaries about issues of knowledge, evidence and ethics. The delays that occurred for practical reasons helped keep some ethical deliberations at bay. If a procedure did not immediately by its design suggest a certain perspective, premise or problem, it would not be considered relevant – or rather, not considered at all. This gives a very pragmatic outlook, and is in accordance with what Susanne Lundin (2012) states concerning her study on ethical reflexivity in biomedical researchers:

“The fact that everyday practice is connected to professional ethics leaves no visible effects on how biomedical knowledge is produced – as I have discussed here, ethics mirror the conditions of the laboratory in a pragmatic way” (2012:35). This effect, being more or less a “natural” part of the black boxing process that inevitably needs to take place in order to progress the research, fortunately does not need to be completely opaque.

The ethnographic method can help visualize to researchers, stakeholders and to the outside world what is unconsciously being locked into the black box of scientific negotiations. O’Dell and Willim (2015), among others, raise questions concerning “for whom is ethnographic work being done? How might it engage society, or even contribute to processes of change? In what ways can academic work be participatory?” (2015:98). My field of research is an example of where ethnographers can offer a valuable oscillation between an insider-outsider perspective and help add new knowledge and insights, which may have potential to raise awareness and spur change in some scientific processes. It is crucial that we continuously develop and evaluate our ethnographic methods, so that they better target the practical dimensions of possible ethical or philosophical blind spots in research processes.

Medical ethicists can offer valuable perspectives on how different choices that ethical dilemmas offer relate to different philosophies of ethics, and give practical advice based upon that. Still, their more abstract working methods do not lend themselves as well to scrutiny of practice and the effects of routinized and unreflected behav-

our. To some extent, the ethicists themselves often also need to be part of the black boxing process in order to further the progress of the research, hence locking some premises and practices to each other while excluding others.

Ethical questions concerning guidelines and permits without doubt still need to be raised and discussed in board meetings. The crucial role of policies and guidelines in regulating the demeanour of science and research cannot be stressed enough. However, since research in practice inevitably enters a state of oblivion when becoming mundane to its practitioners, it needs to be examined and addressed just as carefully as do guidelines and policy documents.

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### Notes

- 1 For the limited scope of this article, I had to omit definitions, the historical background

and discussions of the concept of evidence-based science and its consequences. I will be referring to evidence-based science as a referential framework without further developing the concept considering its presumed ideal logic and rationale in science theory. My interest for this article primarily lies in how the staff of the project work practically to achieve this ideal and the legitimacy that comes with it, rather than what it is thought, or ought, to be. Thus, for me, evidence-based science here is equal to the practice and procedures of the trial, as well as how the material and machines are used to achieve it. Last but not least, the discussions and deliberations on how to best achieve reproducibility and mobility of the fetal cell suspension and the procedures of its production, is of course of the utmost importance here.

- 2 In vitro fertilization, an artificial reproductive technique.
- 3 Emma is an alias given in order to protect my contact's privacy.
- 4 Entering the field of biomedical research and practice as an ethnologist, I also affiliate with a modern and strong tradition of Lund University ethnologists researching relations of health, illness and sickness to the cultural and epistemological consequences of medical research and practice – as well as the boundaries of life and death, of nature and culture, of body and mind and the body and its parts, in medical research (see e.g. Hagen 2013; Hansson 2011; Idvall 2006; Jönsson 2013; Lundin 2015; Lundin, Liljefors & Wiszmeg 2012; Lundin & Åkesson 2002).
- 5 Besides what will be used for analysis in this article, numerous observations in laboratory and interviews have been performed throughout these years. These materials are excluded from analysis here since the topic of this text is delays.
- 6 I am aware that actor network theory (see e.g. Latour 1999;2005), from which the concept

of “black boxing” has been borrowed, has a strong focus on things and materiality. The same is true for ethnology, which has a strong and long tradition of investigating the role of things in everyday life (see e.g. Löfgren 2015). Things are also very present and active in my empirical material, but I have still chosen to omit any deeper theoretical and analytical elaboration on the topic. This is primarily due to the need to limit my analysis for the purposes of this article, but also because the things in this specific empirical material are, as will be shown, primarily experienced by me as abstract entities in the discussion and negotiations of the staff. I believe the abstract level would disadvantage an analysis of things.

- 7 A fluid inducing a state of inactivity and metabolic depression in the cells, hindering development into neurons.
- 8 A special kind of nippers used in medicine and medical research.
- 9 In Swedish: Inspektionen för vård och omsorg – IVO.
- 10 <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A31998L0044> (retrieved 9 March 2016).

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Paper III







# Transforming trash to treasure: Cultural ambiguity in foetal cell research

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## Abstract

### Background

Rich in different kind of potent cells, embryos are used in modern regenerative medicine and research. Neurobiologists today are pushing the boundaries for what can be done with embryos existing in the transitory margins of medicine. Therefore, there is a growing need to develop conceptual frameworks for interpreting the transformative cultural, biological and technical processes involving these aborted, donated and marginal embryos. This article is a contribution to this development of frameworks.

### Methods

This article examines different emotional, cognitive and discursive strategies used by neurobiologists in a foetal cell transplantation trial in Parkinson's disease research, using cells harvested from aborted embryos. Two interviews were analysed in the light of former observations in the processing laboratories, using the anthropologist Mary Douglas's concept of pollution behaviour and the linguist, philosopher, psychoanalyst and feminist Julia Kristeva's concept of the abject to explain and make sense of the findings.

### Results

The findings indicate that the labour performed by the researchers in the trial work involves transforming the foetal material practically, as well as culturally, from trash to treasure. The transformation process contains different phases, and in the interview material we observed that the foetal material or cells were considered objects, subjects or rejected as abject by the researchers handling them, depending on what phase

of process or practice they referred to or had experience of. As demonstrated in the analysis, it is the human origin of the cell that makes it abject and activates pollution discourse, when the researchers talk of their practice.

## Conclusions

The marginal and ambiguous status of the embryo that emerges in the accounts turns the scientists handling foetal cells into liminal characters in modern medicine. Focusing on how practical as well as emotional and cultural strategies and rationalizations of the researchers emerge in interview accounts, this study adds insights on the rationale of practically procuring, transforming and utilizing the foetal material to the already existing studies focused on the donations. We also discuss why the use and refinement of a tissue, around which there is practical consensus but cultural ambiguity, deserves further investigation.

## Keywords

foetal cells, embryos, abortion, transplantation, pollution behaviour, ritual, foetal waste, abject, embryonic ambiguity

## Background

Besides being a source of potent cells in regenerative medicine, the embryo is a product of the transformative states of pregnancy, birth-giving and abortion, and is therefore associated with the margins of life and death. Objects associated with these borderlands are often culturally considered holy as well as threatening. Embryos are therefore symbols – or icons – of life itself (1), of innocence as well as of sin, of vitality (2) and of potentiality (3). In Parkinson's disease research, cells are harvested from aborted embryos and processed into cell suspension to be used for

transplantation in a medical trial. So while the foetal cells<sup>1</sup> are, in one way, isolated from the outside world, they still have connections to the surrounding society in many ways. Their origin extend to the practical work (see e.g. 4, 5, 6) that is done in the clinic – to the wombs and minds of aborting women and their families – through the different facilities handling the foetal material in different stages and the hands of midwives and researchers mobilizing and refining it, as well as into the minds and brains of future rats and patients, and into the hopes and dreams of the media and the afflicted (7). There, it highlights the same issues as Douglas's 'concept of pollution behaviour, namely, that the foetal cells are something that can be both specific and formless; that they can create order or be a disorder; that they may give life, while a potential life is ended (8). Therefore, it poses conceptual problems for the researchers dealing with it practically on a daily basis in the laboratories as well as in relation to the outside world.

In this article, the anthropologist Mary Douglas's (8) concept of pollution behaviour is suggested as a key concept to understand the cultural processes of turning the marginal, aborted, abject (9) embryo, from trash to treasure in a biomedical setting. With the concept of

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<sup>1</sup> The term *foetal* will be employed throughout the article when referring to the procured tissue and the cells, as well as to the processed cell suspension itself. The term *embryo* will however be used when referring to the donated abortion material as a whole, as it best describes the developmental stage of the donations. Even though the trial in the study mainly uses tissue from donations developmentally defined as embryos, their website defines the cells used as foetal. Therefore that terminology is adopted when referring to the processed tissue, the cells or the resulting suspension. This choice of term also minimizes possible confusion with human embryonic stem cells (hESC). The term *embryo* refers to the time period of development when organs are formed. In the human, it is defined as up to 7 weeks + 6 days post-conception (pc). The foetal period starts from 8 weeks + 0 days pc. It should be noted that the trial occasionally procures and processes cells from what are by definition early aborted fetuses, up until 10 w pc. This is because measurements and calibrations sometimes are uncertain concerning the exact gestational age pc. Therefore all donations within a period of 5–9 w pc may be used in the trial. The tissue may therefore sometimes by definition be derived from tissue within the foetal developmental stage. Up until this point in development, the embryo does not have all the bodily organs formed, nor functioning. No circulation system has developed yet and the cells survive in part independently of microcirculation.

pollution behaviour, we want to examine different strategies used by – and expressed in accounts of – neurobiologists to handle cognitive and emotional challenges emerging from the processing of aborted tissue in a foetal cell transplantation trial. We do this by connecting interview accounts focusing on their professional practice to previous observations of it. The article offers a cultural perspective on how foetal cells, as scientific artefacts of foetal origin, can be considered marginal objects of waste, both culturally dangerous and simultaneously powerful. Earlier studies have raised similar questions. Ariss (10) as well as e.g. Waldy (11), have conceptualized foetal materials as cultural waste. Pfeffer (12) and Kent (13) have mapped cultural and emotional motivations for foetal donation for stem cell research, among possible donating women in Great Britain as well as among different practitioners facilitating donation. Focusing on practical as well as cultural strategies and rationalizations of the researchers receiving and processing the tissue, this study adds insights on the rationale of practically procuring, transforming and utilizing the foetal material, thus supplementing previous studies focused on the donations.

Responding to the issues that the researchers face through the framework of pollution behaviour, we hope to offer the researchers an explanatory model, and also to give meaning outside the biomedical paradigm. One such example is the use of foetal cells derived from aborted embryos in research and in clinical trials on neurological disorders. The neurobiologists are recurrently reminded of the origins of the foetal material in their daily work in the laboratory. Its double status as an aborted, private kind of waste, as well as an available source of vital, valuable regenerative cells makes it ambiguous (cf. 14) – and gives it what will here be described as ‘embryonic ambiguity.’ Different tasks and stages of the cell refinement process either recall or obscure the relation of the cells to the aborted embryo and to the donating woman. As these cells are also scarce, their regenerative value makes them a rare commodity (15, 16). The number of abortions performed in the near region does not cover the required amount needed to secure enough cells for the patients, and embryos have to be transported between the cooperating centres in the trial to try and cover each other’s needs. Different strategies and attitudes are needed and developed in the cell laboratory and the animal transplantation laboratory,

to deal with the relation between the practical cell refinement process and the more figurative and symbolic cleansing process, as well as with the scarcity of cells – in short; with the ‘embryonic ambiguity’. It is not always a smooth and unproblematic procedure. In these frictional events, the development of such strategies is highly visible. Therefore they make up a methodologically fruitful arena of examination.

This study follows neurobiologists in their work in a transplantation trial, in which they employ the regenerative potential of aborted embryos. They harvest dopaminergic brain cells from aborted embryos, which are used in transplants called cell suspensions, to patients in the early stages of development of Parkinson’s disease. These cells have the ability to alleviate and possibly reverse symptoms of the disease, by partly restoring the patient’s lacking dopamine production. Showing a high success rate in using foetal cells to a larger number of Parkinson patients is of very large significance to the research team and to the trial, as well as to the broader field of cell transplantation research as a whole.

## Methods

The two interviews in focus for this article are contextualized by a body of ethnographic material consisting of observations in the cell and animal laboratories, as well as participation in the regional planning meetings of the trial during two years. The observational and fieldwork notes amount to 215 handwritten pages in total, of which about 70 pages consists of laboratory observations. Approximately 30 hours was spent on observation in the laboratories. There is a smaller photographic documentation of the processing of cell suspension. The material also includes 25 documents; official as well as so-called grey documents,<sup>2</sup> They range from ethical permits to descriptions of good clinical practice (GCP) and standard operating procedure (SOP). The research material for this article is arguably not very large. In exploring an issue of general cultural importance and applicability, however, the aim is not to achieve generalizability of the results. By accounting for what we argue are some expressions of the

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<sup>2</sup> Internal, unofficial documents.

mechanisms of pollution behaviour, the article gives higher transparency to an activity that is opaque to many outside the biomedical field. Moreover, it is often surrounded by biomedical parlance and terminology, the cultural side of ethics risks going unexplored. This is unfortunate, as such issues are of great societal interest and importance.

The empirical basis for this article is exclusively ethnographic research, which is central for studying the activities of the laboratories (3, 4, 5). Ethnographic methods are well adapted to this kind of study, where the aim is to reach and visualize mundane and vague social and cultural processes. The point of departure of these methods is for the researcher to “be there”, and in doing so, reach into and problematize the practices in the situations in which they occur (17). These practices are not always verbalized in the setting, but may be lifted and discussed in interviews with the participants at a later point. This allows the researcher in the laboratory to reflect upon the events and thereby also broaden as well as deepen the common understanding of the events (18). The material described above forms the basis for the argumentation in this article, using the two interviews as main means for visualizing and verbalizing the findings and the analyses of them. The interviews were conducted following upon repeated observations of the daily tasks of the researchers within the cell and animal laboratories of the trial. The aim of the observations was to see how the materiality of the trial – such as equipment, machines and foetal tissue – was made to come into correspondence with the conceptual instructions and regulations of the documents, through the manual skills of the researchers in the laboratories when manufacturing foetal cell suspension. The interview accounts are focused on the researchers’ professional practice, and have been preceded by observations of these same practices, and by a study of the documents guiding the process. The materials are then connected to each other, in order to create a fuller picture of the scientific practice, materially as well as conceptually.

The interview guides were designed for discussing and elaborating on the findings from the observations, and focused on the researchers’ perception of the relation between the conceptual and the material when producing the cell suspension. The result was two extensive semi-open-ended interviews lasting 1.5–2 hours each, with two junior neurobiologists

in their thirties, given the aliases James and Emma for reasons of confidentiality. The interviews invited elaboration together with each of them, on different cultural and emotional meaning and strategies that the foetal cells enact with them in their daily work in the trial. As the interviews connect philosophical and moral issues with practical laboratory tasks and work experience of the researchers, they offer an understanding of how the materiality of the embryos sometimes works together with, and sometimes against, their professional skills in practice – now and then creating tensions in the processing of foetal cell suspension. In the interviews, the researchers gave accounts of their work in the laboratory. The subsequent analysis of the accounts was geared to how they manage emotional and cognitive challenges. The present article reports on the discursive strategies they employ to talk about the process of relating to the foetal material they handle in their daily work routine. Their experience of friction in interaction and in communication in the laboratory work between staff of similar, as well as different, professions is explored. Their reactions and responses in the interviews and their argumentation around their professional handling of foetal cells are of course personal and non-generalizable. The crucial point here, however, is the way in which their personal strategies function to mediate between the standardizations of the laboratories and the medical trial conditions and contexts that are addressed in the regulating documents which are also part of the empirical material – and a broader social as well as cultural landscape in which the research, as well as the researchers themselves, are situated. The scripts from the interviews form the empirical basis for this article, and the quotations discussed in the Results section are excerpts from there.

Wiszmeg constructed the ethnographic material as part of a broader dissertation project, and Hansson and Lundin have supervised her in this process. Wiszmeg performed the first step in the analytical process, where the empirical material was thematized. In the next step, Hansson and Lundin read these themes carefully many times and looked for biases. In step three, Wiszmeg theorized the themes and translated them into categorizations and conclusions. In this stage Mäkitalo has been connected to the analysis work to obtain a fourth opinion and for an analysis round on the overall conclusions. Widner is medically responsible for the trial



studied here and has provided the medical competence for this article, by reading it through and correcting the analysis according to medical standards and terminology.

## Disposition

First, the cultural role of dirt, waste and the management of it by pollution behaviour will be presented as conceptualized by Douglas (8). These concepts will thereafter be elaborated on to specifically discuss foetal material as an abjective (9) waste product (10, 12). We discuss how the material is made usable and thus reintegrated to culture and society by pollution behaviour. Next, the neurobiologists and their work setting will be briefly presented ethnographically, as an introduction to the analytical part of the article. Following upon that, the interviews will be discussed thematically, using the concept of pollution behaviour as an analytical model. Finally, the implications of the findings will be elaborated upon in relation to modern developments of regenerative medicine at large. We discuss why expressions of ambiguity and discomfort in the interface of private versus professional aspects of the researcher as person should be examined in the borders of science(s) and society.

## Theory: Dirt and pollution behaviour

Douglas's *Purity and Danger* was written as an attempt to create a general and systemic theory of ritual cleanness in religious or spiritual ritual. As such it is far from today's high-tech laboratories, but as we shall see in the following it is highly relevant for gaining an understanding of the cultural and societal function of the laboratory processing of foetal tissue into cell suspension as a cultural phenomenon. It is largely due to the cultural mechanism transforming aborted embryos from waste into resource that they are possible to utilize as a resource for cells in regenerative medicine.

To reach a more general understanding of the procedure as a form of ritual cleanness, we need to look at the opposite: ritual pollution and the role of so-called pollution behaviour in making what is considered dirty clean again. To understand the dialectics of pollution behaviour it is

essential to understand that the function of the taboo is to protect local consensus as well as to confront the culturally ambiguous in a community (19, p. 11). Anything that challenges social and cultural classifications and patterns within this system activates so-called pollution behaviour, which excludes the specific matter or object from this order as being dirt or waste (8). Dirt is basically and generally, in Douglas's account, 'matter out of place' (19, p. 44, 50). There are indeed designated places where different matter should and should not be located, and the categorization work behind that notion is itself a sign of cultural activity. When pollution has occurred by displacement of such an object, the community needs to clean it up. This is done in many different ways depending on the context and the type of pollution, but it all serves the same purpose, which is to neutralize a threat and to reinstate communal social and cultural order.

Applying Douglas's concept of pollution behaviour (8) to the use of foetal material in regenerative medicine illuminates many of its processes. The first one is the making of aborted embryos or foetuses into waste, and a source that is possible to utilize for societal purposes generally conceived of as good. Labelling the aborted foetus as waste makes the foetal material available for research. The action of utilizing the resource has been legitimized with the argument that it is the economical and responsible thing to do in a medical economy with scarce resources of biological tissues. Not using it then would in itself be an act of wasting (8, 10, 11, 20). Labelling the foetus waste makes it profane, worldly. To bring meaning to the death of the foetus and reinstate it into social and cultural order, it needs to be refashioned so that its vitality may be harnessed for other positive purposes. It needs to be transformed from *trash to treasure*. It can now be manipulated, made of use for worldly purposes and commodified. The harvesting and use of foetal material is therefore easily defensible, since its holy status has already been compromised by abortion. Using it is then seen as the right and rational thing to do since it offers people healing and redemption.

Donations of tissues, cells and organs in medicine are most often considered gifts (10). When a gift is given, it is the recipient's to care for and to use within the limits of a social and cultural contract. The gift-giver or donor has given up the right to influence subsequent events

concerning the gift or donation, and is not supposed to expect benefits from the donation. At least, this is the idea of altruistic donation, which is prevalent in a Northwestern setting of medicine and care (10). Still, a reciprocal relationship in donation is common for other kinds of reproductive tissues or products, such as IVF embryos considered left-overs (12), or cord blood donation (21). Interestingly enough, no obvious mutual benefit can be discerned in the case of donating aborted foetal tissue, even if it has been a widely accepted explanation that it may assist the aborting women in a possible grieving process (12). What complicates the donation of aborted foetal material is that, while it is the aborting woman's right (in contemporary Sweden) to decide on its use or disposal – the foetus in itself has had a theoretical chance of becoming an autonomous individual, a biographical person. It has no legal status in itself, but is considered a tissue part of the woman's body and therefore treated as a tissue donation<sup>3</sup> (12).

In debates concerning abortion and experimental or therapeutic medical use of foetal material, questions arise as to whether a foetus is yours to give as an aborting woman. In a contemporary Swedish context, it belongs to a pregnant/aborting woman judicially (and practically), but is still seen as an organically vital entity on its own even if it cannot survive unaided outside the uterus. The potentiality of life and personhood in foetuses and embryos still trigger unease, insecurity and cultural, social and philosophical ambivalence, no matter what national law and jurisdiction dictate. One way of understanding the ambivalence that an aborted embryo enacts is that abortions – spontaneous or intentional – generally are considered a wasted pregnancy in medical discourse, and hence are examples of biologically unproductive females. Even menstruation is then labelled as waste, since it is a wasted ovulatory cycle (10, 11). Such discourse reduces women to their reproductive potentiality, but also highlights the weight our society still today gives to fertility and reproduction symbolically. Another is that aborted embryos can be said to 'hover on the borders of selfhood' (10, 11, p. 74), since they are both associated with a subject, but being dead, also fully an object. Being an object calls for symbolic

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<sup>3</sup> See Swedish Transplantation Act 1995:831, and the bylaw SOSSF 2009:30.

classification. It needs to find a place in the world. Since it is also connected as an object with death and decay, it is partly also associated with dirt and waste. It is something that the body of the subject disposes of, such as faeces, urine or in this case; an embryo. Such discharges may trigger disgust, as they are considered unclean. Using the terminology of the linguist, philosopher, psychoanalyst and feminist Julia Kristeva, the aborted embryo can be understood as an abject (9). The concept has previously been explored in relation to foetal material by Ariss (10).

As the majority of society is content knowing that the aborted foetus is put to good use in cell transplantation research, it is researchers such as neurobiologists and cell biologists, who need to take the remaining and practical steps toward cultural and biological reintegration. They need to provide reassurance that the confidence invested in them by society is properly respected and that the foetal cells are really used as well as possible. This is when the practical refinement of waste to resource actually takes place.

## Results

### Observation of laboratory procedures

When entering the cell laboratory where the tissue starts its transformation, the laboratory personnel needs to change clothes and disinfect in an airlock room, before going into the laboratory. In the room there is sharp white lighting from fluorescent tubes, facilitating an easy overview of all surfaces and equipment. The room is quiet and free from odours. There are airflow hoods, microscopes, incubators and cell counting machines, as well as smaller instruments for dissection, as well as pipettes, tubes and disposable gloves in marked drawers and boxes. It is here that Emma and her colleagues process the cells into suspension. The procedure involves receiving an aborted and donated embryo from the nearby abortion clinic; dissecting it, collecting its brain, and then dissociating the cells from the relevant brain region in different solutions, until a so-called cell suspension is what remains. The suspension consists of a liquid preserving and creating a good

environment for the cells it contains. This injection liquid is the product that will be transplanted in rats or in human patients.

The animal house and laboratories, where the cell suspension is transported when it is not transplanted to human trial subjects, are located behind a totally anonymous door. In the so-called stereotactic laboratory,<sup>4</sup> researchers are already working on anaesthetized female albino rats in their benches. This is where James and his colleagues transplant the foetal cells to lab rats, whose dopamine production has been impaired to mimic the symptoms of Parkinson's disease. The room contains three working benches with miniature so-called stereotactic frames for brain transplantation to rodents and fume hoods. The cages have been fitted with wooden chips, water, food and nesting material. The locale lies in relative darkness, except from the small but intense spotlights above the operation tables, focusing both the light and the concentration of the researchers on the rats to be operated on. It is in the premises described above that the major part of the transformation of aborted embryos into an injectable, regenerative cell suspension – as well as the transplantations of it to rat, forming the scientific basis for decisions on subsequent transplantations to human trial subjects – takes place.

In the interviews that followed upon observations in the premises described above, James and Emma often spoke of the cells in ways that made visible their different roles and functions. The cells emerged differently, depending on the practical relations between the cells and the researchers, as well as in between researchers of different professions or tasks. The cells were often assigned double roles and characteristics simultaneously in the content and character of conversations and practical situations with colleagues, as described by the participants. This embryonic ambiguity also showed discursively in the interviews themselves, when the participants referred to the embryo or the tissue. Exploring these relations, some distinguishable themes based on the roles of the cells emerged in the analysis of the interview material. Categorizations of these themes will now

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4 Stereotactic surgery is a minimally invasive kind of surgery in which a three-dimensional coordinate system is used for locating the sites of action in the body when planning and carrying out an operation.

be discussed in relation to ritual and pollution behaviour in the analysis, using interview excerpts. The article starts by addressing the foetal cell and the processed suspension mainly as a scientific object and a resource in regenerative medicine.

### Cells of human origin

It is not only the practical refinement of the foetal tissue that transforms it into a possible regenerative treatment. The expressions and concepts used when talking about the foetal material also work their magic in making the material emerge as an appropriate object from which to harness regenerative vitality. To adjust the language internally as well as to an external audience is one way of letting science cleanse the human dirt of the foetal material, thus making it into a neutral scientific object. This linguistic cleansing ritual is something that arguably starts already in the abortion clinic, in which the staff wishes to minimize foetal connotations of a potential baby (12). In the cell laboratory, the ambiguity of the embryo as a symbol usually works in favour of the researchers taking on the task of refining it. Occasionally these linguistic shifts even reveal the hoped-for development and success of the trial for the researchers.

James: Really, you'd say tissue or something, rather than embryo or, you know... Some people might say like "products of conception". Or "abortion material" or whatever you know. We usually say "tissue" or "embryo". [...] Today we got [...] these two patients who consented, [...] and some people will go "okay, well there's two patients; we'll have two embryos"... Some people will then, refer to it that way. So that happened today as well, and [...] I was like "well no we don't, because it's just people who consented, we might not collect anything because, either they're destroyed or..." you, know...

By conflating the consent to donate with an aborted, available and usable embryo, a wished-for future has been envisioned and evoked with the help of a metaphorical spell whereby the consent *is* transformed into the embryo. Simultaneously, through the change of a few words, the imagined

available embryo has made a cognitive leap in the mind of the researcher, from being a waste product to being a resource. The consent is conflated with the potentiality of the cells, but its origin is thereby also hidden in discourse.

In this way metaphors not only affect our communication but also structure our perception and understanding of events and concepts from the very beginning (22, 23). In other words, we cannot think without metaphors. The use of foetal tissue in regenerative medicine seems to be defensible by the inbuilt moral argument that ‘saving’, in contrast to ‘wasting’, offers (24). The connection to another living human being – and the fact that the embryo could potentially have achieved personhood itself – makes it too human to ignore. The metaphorical dichotomy of ‘wasting’ versus ‘saving’ has the power to ease the discomfort that the human origin of the tissue may bring, by at least knowing that it is made use of and not thrown away.

To be capable of being made into a resource to utilize, the embryo needs to be mentally, as well as emotionally and culturally rejected – in this case by being linguistically substituted for, disguised and hidden in speech. When engaging practically with the material in laboratory, its humanness emerges in other more evident ways, making such mental leaps more far-fetched. Still, the humanness also seems to disappear easily through the same kind of logic, when the human features of the embryo are physically removed in the laboratory.

Emma: That aspect totally disappears.

Andréa: When does that happen, do you think? I mean, in your work?

Emma: When [...] the embryo first arrives, then sometimes it occurs to me: “Yeah well, this could potentially develop into something”... but then when you start cutting the head off and take the mesencephalon (the relevant brain region) out... then it is just a piece of tissue that...

Andréa: Yeah, right... (pause) So as soon as you start using your tools... its kind of...?

Emma: Yes, and take away the facial tissue, then it’s not in a way, like, well you don’t think like that anymore...

When Emma does not, literally, need to face the foetus anymore, it becomes an object in her hands. The removal of human features may very well be interpreted in this context as an unmasking of its inner potential, as a source of cells for science and society. This cleansing ritual is meticulously choreographed by standardized guidelines and releases the great hidden vital powers of the embryo. As Douglas argued, it is the identity that makes rubbish dangerous (8). When marks of origin and identity are removed from the waste, so is the threat it constitutes.

Nowadays James does not have to engage with the dissection of the embryo, as he also did in the past. Now he only receives the ready-made cell suspension for transplantation. When the features making us recognize the embryo as human are already removed, and its format is totally transformed, the situation is different. It has now entered a new phase in the refinement process. It is a new starter product with a new trajectory altogether.

James: But I mean that's strange in a way because... in what I do now I just get like, a cell preparation. I haven't seen where it's come from. It's very unproblematic for me now. It's just: "get it, do it". The same as if I got cells from mouse tissue or rat tissue or from cultured cells, you know, I don't feel any difference. But that's when I've had no hands in the, the kind of, acquisition of the tissue. [...] But I've also been exposed to it. If I was told the age (of the embryo) I can in my head imagine what it looks like and...

Andréa: You have a reference?

James: Exactly, yeah, but then I don't do that (imagine it).

The cell suspension is to the embryo as what the steak in the supermarket is to the cow: refined and cleansed from features showing the origin of the species. In a sense, a reversed ritual logic has been activated. As metaphors or metonyms structure our experiences (22, 23), they are common components in ritual too, helping to enact the wished-for result. Concepts of origin, whole and part plays important roles in this process (25). But rather than admitting and underscoring the relation between embryo and cells, the processes in which the researchers engage work to erase or obscure this relation. However, as we have seen in the quotations, such an endeavour is not easily achieved throughout on all levels. The connection of humanness



to the cells they procure is re-enacted on a daily basis. It re-emerges in the interactions of the scientists, the connections to aborting women, and in the interactions with the outside society. In the larger community and society outside biomedical research – in which of course the researchers are also members – the cells are usually part of a human embryo, and the embryo has once been connected to a woman.

Whether the cells are expressed as considered part of the embryo, equal to the embryo, or not related whatsoever in the accounts of the researchers, is – as has been repeatedly shown in these accounts – therefore mainly a question of the researchers' connections to different phases of the process, and their individual relation to and experience of these phases. Still, the cells to some extent resist being easily cleansed of their pollutive properties of sex, death and flesh – as well as the reincorporation into cultural and scientific order.

### The cell as object, subject and abject

To make an aborted embryo into a resource, it first has to be acknowledged as one in culture and society. Labelling the foetal material waste can be said to release the latent 'biovalue' (11) of the embryo, and the material becomes an available scientific *object* whose regenerative qualities may be harvested and utilized. Its great therapeutic value in the potential to bring, prolong or enhance the life of another being makes a perfect argument for use in regenerative medicine and neuroscience.

In the following, the researchers talk of their professional tasks mainly in relation to the status of the cells as objects with quality and potentiality. By doing this, they confirm a mutual vision of a resourceful vitality, as well as a common effort to harness it. Here they elaborate on how they view their respective roles and responsibilities within the trial in relation to its goals:

James: I guess my main goal is to ensure that, to kind of to test and validate the quality of that (the cell suspension). So, I think that my main goal has been to, kind of, assess and validate as best we can, the product that then will be put into the holes (in the brain of the rats). You know, it's the first part of the study.

The foetal material is here seen as a medical object that can be used to produce cell suspension. James argues that it is the quality of the cell that is central, something that is also highlighted by Emma: “It has to be good quality all the way. I mean the embryos need to be of good quality.” However, capturing and making use of these objects’ potentiality in the standardized way required in evidence-based medicine proves hard when using foetal material. It keeps eluding the researchers time and again. This is something that James works hard for, to have an outcome of good quality: “We don’t know what predicts that so, it’s just more or less seeing how often we can get a good... outcome”.

Both Emma and James have a clear focus on the work of ensuring the quality of the cells, and they struggle to process them procedurally, as required within evidence-based science. The variability as well as the scarcity of the material makes it difficult. The foetal tissue seems to resist standardization as well as predictability in the hands of science, since it is an organism as much as it is an object. It seems difficult to disarm as a source of polluting uncertainty and symbolic threat. Not only do the cells themselves behave wildly and resist the common task and vision of the trial in becoming pure, harnessed and reusable objects. The researchers themselves sometimes acknowledge the vitality of the cells as a life force in its own right, and as a kind of being or existence to be taken care of; as Emma describes it, the cells “cannot be stressed”. In her practice this is central how to work with the cells:

Emma: How hard you pipette them and that, it’s just a feel you have for it. [...] It’s also something that we don’t have any exact protocol for how to do it. [...] I think of them as resting. – That in a way they lie resting there. That they get a chance to just lie there. [...] Until it is time... because you don’t want to do something to them, I mean you don’t stimulate... To a certain degree they will probably divide and so on, but since they are small tissue pieces still it will not happen to any great extent. But of course, one can imagine it happening, at least in the beginning... But otherwise, it’s more a matter of trying to imagine them just lying there sleeping.

Imagining the cells as remains of an embryo with the former possibility to develop into a human being may have influenced the way in which the

researchers talk of the cells as subjects, as more advanced organisms. Acknowledging the cells more in terms of subjecthood, the researchers are increasingly reminded of their human origin. James highlights this when he says: “to give them an environment that’s protective and allows them to grow. Because if you didn’t do that, they’d kind of be attacked and just die off, so...”

Modern medical techniques – for example, pre-natal sonograms and diagnosis, foetal surgery, and assisted reproductive techniques including pre-implantation diagnosis – can be said to have pushed the boundaries of personhood, making the subjectivity of the unborn living foetus a philosophical and moral issue of debate (see e.g. 26, 27, 28, p. 212). But it seems difficult to entirely escape the pollutive fatality of the foetus, even though it is a requirement for the trial to succeed and for cultural reintegration of the aborted embryo to take place. In this way the cell is not only conceptualized as an object or a subject, but as something in between. Being a rejected discharge of sorts, it can be understood as an abject (9), thus triggering disgust.

Emma: In the beginning you can feel that is in a way a bit... dirty. The tissue you get... because it has bacteria in it. I mean it came out, through that passage, and it is not really very... there is lot of bacteria and stuff there. You see blood that comes with it and... There is a risk that you could potentially be contaminated yourself too.

The lingering pollutive properties of the aborted embryo are not solely cultural. As a source for a potential transplant in regenerative medicine, it also needs to be controlled for and cleansed from bacteria and potential pathogens. However, not all contagion is biological. There seems to be a migration in meaning concerning the kind of dirt associated with these cells. James talks about this: “I mean I guess, because it’s been treated so much like, washed and dissociated with enzymes and then cleaned again and washed, you know, then it’s, I guess it’s... sterile (laughs)! It should be sterile.” The quotation seems to leave us with a question more than an answer. It reveals a kind of uncertainty as to whether we can trust that the sterilization process has really succeeded on all imaginable levels. And indeed, the connotations that an aborted embryo has seem somewhat

hard to wash away, no matter what components are used. This is also something that Emma talks about: “Really, I mean it is tissue that comes from... yeah, vaginally, and there are bacteria and all sorts of stuff. It’s not really very clean. I mean, I feel that stem cells can be controlled in another way.”

It can be argued that there is good reason to be wary of contaminants when working with material that has had so much contact both with the insides of the human female body and with the vaginal canal. However, it was mentioned numerous times during planning group meetings that the serology and pathogen tests looked so very good generally, and that not much contamination except for harmless lactobacillus, normally found on healthy skin, was usually found. Still, that did not seem to take away the fear of the polluting embryo. It is, as discussed in the introduction and in the theoretical section, not only by its biological processes that the foetus or the embryo is a risky object. The dirty properties of the embryo remind us in different ways of fleshy humanness, as well as of an often culturally unsanctioned female sexuality. Even if the women from whom the material is collected may be labelled risky mainly because of possible infectious disease; they may be labelled so *also* by going through an abortion, which is often perceived as connected to sexual behaviour perceived as risky and irresponsible (12, 13). Here, we want to underscore that the interviewed researchers in no way signalled that this was part of how they view the aborting and donating women. However, it can be argued that such notions strongly still influence the ways in which we all symbolically interpret meaning and value in the world.

## Discussion

This article is an attempt to develop a framework for interpreting the transformative cultural, biological and technical processes involving practically as well as symbolically marginal embryos. Using Douglas’s concept of pollution behaviour combined with Kristeva’s concept of the abject, we highlight different discursive strategies utilized by the researchers to handle cognitive and emotional challenges posed by the processing of symbolically ambiguous foetal tissue.

Making claims about pollution behaviour and its implications in the processing of foetal cell suspension, relying on a sample of only two interviews, may seem bold. The results should therefore not be considered generalizable to all researchers working with foetal material, but rather illuminate and elaborate on some social and cultural values and meanings that have been connected to the embryo as a symbol (1), and therefore arguably influence the ways in which it may be handled practically. As there are other studies of regenerative use of foetal material in medicine suggesting similar results, it adds weight (10, 12, 13).

We found that the practical, physical removal of the human features of the embryo – as well as the metaphorical and symbolic cleansing in and by language of the foetal material (20, 22, 23, 24) – seems to help the researchers escape the uncomfortable and polluting humanness of the embryo, in a variety of practices and situations. It also takes the material a step closer to the pure source of vitality that is the cell suspension. The practical work of refining the tissue cooperates with linguistic work (28) in order to disconnect it from all human ties and features, as well as from its connections to decay. The inherent vitality of the embryo is literally hibernated in time and space and made mobile. The essence of life has eventually been disconnected from death. And, as Douglas notes, death and bodily dissolution is the question to which pollution behaviour and ritual is the answer: “Just as the focus of all pollution symbolism is the body, the final problem to which the perspective of pollution leads is bodily disintegration” (19).

However, the accomplishment of disjoining life from death has not come easy in practice, as has been shown. It takes many different types of labour to make science and culture out of nature. The scientists in the cell and animal laboratories have to master all of this when working hard to tame the unruly foetal cells. They must manage the materiality of the cells and also, as has been shown here, their linguistic treatment. The researchers take on the task of refining the aborted embryo from trash to treasure. They may in return enjoy a position in which their otherwise questionable closeness to the dirty embryo will not be questioned. They are protected from pollution by the abject (9), by momentarily jeopardizing their own cleanness to restore social and cultural order.

Rituals involving elements of collective aggression and sacrifice are believed to help create a sense of community. The irreversibility of the sacrifice transforms its participants (25). How may we then understand the sacrifice of the embryo to science? Imposing death on it by abortion seems to protect the scientists from being able to commit any further violence against it. All subsequent handling of the foetal material – no matter what the character – is then understood rather as an act of saving its remaining vital properties. Practically dismembering the embryo under microscope and diluting certain brain cells of it into a suspension would under different circumstances be considered an act of violence. However, when narrated as part of a cleansing process, it has a higher purpose, which is to make trash into treasure and thus protect the community from pollution. The scientists are then – together with the embryos they handle – as professionals, always in a liminal,<sup>5</sup> intermediate, state. They are not only allowed but also encouraged to commit deeds which would in other circumstances have been deemed pollutive. Acting under this circumstantial freedom enables them to take on the burden of responsibility for cleansing the embryo of symbolic dirt. This could be argued to give the scientists shaman-like features or magical powers. And indeed, science seems to hold the powers of magic to cleanse the symbolically dirty and abjective (9) foetal material, as well as to practically transform it from trash to treasure. Scientific practice, in a legitimate way, restores the order of the community, by cleaning the foetal material from its associations with dirt, pollution and liminal humanness.

## Conclusions

It is crucial to understand the rituality and cultural concern surrounding the handling of foetal material in regenerative research. By applying Douglas's concept of pollution behaviour (8) to the aborted embryo, and by understanding it as abject (9), we found that the tabooing of it activates an adapted and sensitized language. The linguistic substitutions ascribing

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<sup>5</sup> The liminal state of professional scientists should be understood in relation to their private self, and as functioning to ultimately reaffirm cultural social order, even if they temporarily disturb it. See e.g. the anthropologist Victor Turner's *The ritual process, structure and anti-structure*, 1969.

different entities to the cells, depending on context and purpose, are indeed connected to the knowledge production of the trials. They enable the use and refinement of a tissue around which there is practical consensus but cultural ambiguity. This may, however, complicate communication and cognitive and emotional processing amongst the involved researchers, due to lack of common definitions. Cultural ambiguities will, on the other hand, always exist and do important developmental value work in communities and societies. The taboo (8) of the embryo helps protect a certain practical core consensus of the research community concerning the rituals involving the cells. This means that, even if there is no consensus about what the cells are, there is consensus about what the cells can do, and what can be done to the cells. Understanding the ambiguous cultural symbols of a community is as important to science as it is to religion and society. It may help us see the interconnectedness between these seemingly separate areas. There is much to suggest that ritualistic pollution behaviour may be used to fully make sense of a situation where no traditional scientific means of knowing can adequately be applied. It may complement other, more scientifically legitimate ways of knowing. In this study, we argue that the ‘embryonic ambiguity’ of the cells, offers the scientists engaging with the foetal material a liminal cultural key role, transforming the material from trash into treasure. This is an important insight into the diverse set of skills employed by biomedical scientists. It is also a valuable contribution to previous humanist research on cultural and ethical aspects of the use of aborted embryos and foetal material in regenerative medicine (cf. 11, 12, 26), as our study focuses on the researchers receiving and processing the tissue, rather than on the parties involved in the donation process (13).

When foetal material asks questions of origin and humanness, of being and non-being, of part and whole and of life and death, pollution behaviour offer answers which the traditional methods employed in the cell laboratories cannot. By neutralizing perceived threats to communities, it also enables progress, development and change. Pollution behaviour may add different types of meaning and understanding also to the laboratories of regenerative medicine, and a broadened framework of action for facilitating the cultural reintegration of abject (9) tissues.

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Paper IV





## 4. Diffractions of the foetal cell suspension: Scientific knowledge and value in laboratory work

ANDRÉA WISZMEG

In the quest for a cure for Parkinson's disease, scientists have travelled many avenues. One is the use of cells from aborted fetuses. These cells have been proven to restore the lacking dopamine production in the brain of the afflicted person. In order to place the cells inside the patient's brain, a so-called cell suspension must be made and administered, which is a liquid produced in a laboratory containing mainly foetal brain cells. This can be transplanted either into rats for research or into human subjects for clinical trials, and theoretically for treatment.

For people encountering the cell suspension, it enters their lives in different ways, giving it diverse shape and meaning; it also gives rise to many different kinds of expectations. Thus, a delicate issue such as the use of the cell suspension, with its foetal origin, provides a good basis for discussing what I would call 'science's understanding of/engagement with knowledge'. Normally when issues of participation in science are discussed, it is done in relation to how stakeholders and otherwise affected people such as for example patients and relatives understand science. The so-called 'information deficit model', where the public was seen as lacking in knowledge and understanding, was a concept common in the research field of the 'public understanding of science' (Evans & Durant 1995; Sturgis & Allum 2004). This model was gradually replaced by views in which engagement and information exchange were regarded as more of a two-way communication between researchers and the public; lay-people's understanding was also seen as a kind of knowledge. The development of a more reciprocal view of knowledge is expressed in the newer concept of 'public engagement with science and technology' (see

e.g. Stilgoe, Lock & Wilsdon 2014). Still, even with the newer terminology and the ideas connected with it, much of the focus is on the ‘recipients’ of scientific results, and less on those who produce them. This is problematic, because it sets the researchers’ views apart as something largely free from values, meaning and desire, as opposed to the afflicted lay-peoples’ views. In this chapter, I will give a more nuanced and complex picture of how scientists value what they do. With the help of interviews with two laboratory researchers, I focus upon how they understand, value and provide meaning to the foetal cell suspension that they work with. I argue that they do it differently, depending on how they interact with the suspension. The aim is to gain a better understanding of how the scientific knowledge comes into being in a scientific laboratory. The analysis thus problematizes how participation can be understood in a laboratory context.

### A diffractive approach

This chapter is based on two semi-structured interviews with two junior biomedical researchers, which I call Emma and James (the researchers have been given aliases in order to protect their anonymity). The interviews focused on the knowledge- and object-production in their respective tasks in a large-scale clinical trial and were based on my observations of their work conducted prior to the interviews. The biomedical project that they are involved in aims to make a definite and concluding transplantation trial with foetal cells from aborted embryos. Both researchers work with the stages of the trial prior to the clinical study. Emma works in the cell laboratory dissecting embryos and preparing the cell material, and James works with transplanting cells to rats and evaluating the cell growth and innervation in them, but he also has experience of working in the cell laboratory. I could thus pose questions to both about the origins of the foetal material and its transformation in the laboratory. I wanted to keep the conversation close to my participants’ own practical experience, in order to gain a better insight into the way this shapes their understanding and how they make sense of the foetal cell suspension, both in abstract and material terms.

The interviews were conducted under somewhat different circumstances. I conducted the first interview with James in English, in a quite empty, but because of background music, noisy, café. This interview was the more extensive of the two and lasted slightly more than two hours.

As will be shown and discussed, it was also more elaborative concerning issues of knowledge creation. It seemed as if James and I were more aligned with each other in researching the philosophical issues of science that I was addressing – or at least most oriented towards understanding each other’s understandings of the issues at hand. The interview with Emma was conducted in Swedish in a meeting room in my office building, also over coffee; it lasted about one hour and a half. I have translated the excerpts from the interview with Emma used below into English. The non-neutrality of the environment may have impacted the interview situation. However, since I had been the stranger in their laboratories and other premises previously, I believe that the shift in environment into my comfort zone of research ideals and practices may have had a balancing impact on our discussions.

The analysis that follows is an experiment and an attempt at making a shift from a reflexive perspective to a diffractive approach in understanding the interviews. Diffractive analysis is a philosophical approach that focuses on practices that take differences into account and considers how differences are made, while reflexivity is generally more centred on sameness, in seeing the self in the other, and vice versa. The difference between the two research approaches might, however, be minimal. Dialogues, interviews, observations and other fieldwork practices are situated in the world and are regulated by the same natural laws and social codes, no matter what philosophical approach you choose to work with. Still, I argue, that a shift in perspective from reflection and likeness to diffraction and difference, may enable different kinds of knowledge. As educational scholars Alecia Jackson and Lisa A. Mazzei have pointed out concerning how to work with empirical material diffractively, it is not what makes something different, but rather *what* difference is being made, that is of importance (2012: 122). A researcher’s subjectivity, for example, is treated as a set of linkages and connections with other things and bodies (p. 135). Rather than it being inherent in a subject, it is highly situational and fluid, with varying durability.

My starting point is an example used by feminist (quantum) physicist and philosopher Karen Barad to explain different kinds of ‘research modes’. She borrowed the example from the Danish physicist Niels Bohr. If a person in a dark room holds a cane, the person can intra-act with the cane in two mutually exclusive ways. By holding the cane firmly, the person can use it to navigate the room; the cane then essentially becomes an

extension of the subject. If the person instead holds the cane loosely, its features can be examined, turning the cane into an object of study (Barad 2007: 154). The metaphor can be interpreted as indicating two ways of research: either subjugating those studied to the researcher's critical gaze, or enacting the social aspects of the setting collaboratively and letting ourselves as researchers be critically examined by our participants. This takes into consideration how the participants hold, in a metaphorical way, the ethnographer firmly or loosely, but also what kind of knowledge they gain by doing so and what they can set in motion. If we presuppose a boundary between the ethnographer and the 'other', we should remember that the ethnographer is not only holding, but is also being held. Much like the ethnographer, the 'other' will use the research situation to explore the world surrounding them, together as well as separately. The researcher, too, will be the researched.

The question of what happens when encountering and interacting with people in fieldwork, and what our responsibility as researchers should be, is an old theme in ethnology, sociology and anthropology, most recently linked to the question of reflexivity (e.g. Clifford 1986; Ehn & Klein 2007 [1994]; Davies 2008; Gunnemark 2011). Reflexivity has been regarded as a necessity when reflecting upon closeness, distance, likeness, difference and the cementing, or challenging, of power hierarchies and structures between researcher and participant. This was, not least, a welcome change after the colonialist mindset in much of the previous anthropological research.

However, there are limitations. Reflexivity as a philosophical concept is based on the optical metaphor of reflection. It thus sustains a strong subject/object divide, and brings to mind the reflection of oneself in a mirror. And even if one believes that social and cultural research *is* close to 'the world' and performed in proximity with objects and subjects, a reflexive outlook in a sense deems this situation in itself problematic, and calls for distancing analytical practices and for rational, cognitive reflection. I consider a diffractive approach to be a fruitful extension and development of the reflexive project, by changing our analytical point of departure from 'how can we, being inherently different, understand each other?' to 'what makes us different, when we are originally the same but ever changing and differentiating?' (Mellander & Wiszweg 2016).

The concept of diffraction is well-known within physical optics (as is reflexivity, arguably). It was introduced to the social and cultural sciences



by the feminist scholar Donna Haraway in the 1980s, in connection with her elaborations on situated knowledges (1988). She presented diffraction as an alternative to the – in her view – dissatisfying philosophical concept of reflexivity. Karen Barad then developed Haraway's reasoning on reflexivity. 'Reflexivity, like reflection', Barad says, 'still holds the world at a distance' (Barad 2007: 87). It does not interfere with, but rather reflects the observer like the surface of calm water. Further, it presupposes a pre-existing split between subjects and objects; an a priori division of the world. Quantum physicist Barad could not accept such a division, since to her, existence is always and ever entangled.

While reflection denotes light that is thrown back from objects and returns to its original source in a weaker state, diffraction describes how waveforms spread out and are distorted when encountering objects – thus instead creating *new* beams of light. Waves of water passing through a hole in a dock, or a beam of light passing through a thin slit, will spread out and create patterns emanating outwards. Overlapping, these patterns will in turn create interference, which can be viewed as diversity created in the world through interaction (or, as Barad would have it: intra-action (2007: 139f.)). This might be in physical shape, such as products or artifacts, or as different understandings or opinions of a topic. A change in one parameter of the experimental apparatus, like the distance between the slits, or in the pace you throw rocks into the water, will lead to new patterns and thus different differences.

Diffraction offers other ways of understanding creations of 'I' and 'other'. It differs from the concept of reflexivity, in that it does not deal with reflection or with the mirroring practice of – as Haraway would put it – 'displacing the same elsewhere' (1992: 4). Instead, it deals with interference and the ongoing creation of differences that matter. It does not leave the 'other' as a mere surface of reflection, but lets us think of them as sources of light and makers of waves in and of themselves (*ibid.*).<sup>1</sup> To create in the world is to make a difference to it; no matter if it is a

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1. Some attempts to use a diffractive approach on qualitative material have been made in recent years, for instance by Taguchi (2012) and Jackson and Mazzei (2012). The latter use diffraction as a way to map out how the interviewed black woman, who teaches at a white university, may 'intra-act with the materiality of [her] world in a way that produces different becoming' (Jackson & Mazzei 2012: 119). They argue that it is not her being black that diffracts her as different, but that the 'intra-action of bodies, discourses and institutions does so' (p. 125). Blackness, and the concept of race in itself, are enacted by these specific intra-actions.

case of the difference between a beetle and spider, making a political or scientific statement or making a vase in pottery class. All these diverse activities become a question of cutting through the a priori entanglement of the world with the use of an apparatus of knowledge production (Barad 2007: 140). As social and material dimensions of phenomena are understood as entangled, I will subsequently neither make hierarchical order, nor even distinction, between these dimensions of diffractions in my analysis. Interpreting and understanding in discourse with others are actions that create symbolic, social and abstract as well as material phenomena. Divisions taking place and differences being made are *necessary* steps for the forth bringing of the world itself.

Knowledge will thus no longer be understood as the result of reflection, or as stemming from straight lines of sight, but as something emerging through disruptive processes (Mellander & Wiszmeg 2016: 103). It is part of the ethnographers' quest to trace the differences that matter in the subsequent interference patterns. I will in the following present a way of reading the interviews with James and Emma diffractively. Between us, we rendered a number of themes concerning the interpretations, values, knowledge and possible roles of the foetal cell suspension, visible.

## Values of the cell

A central aspect of the discussions with James and Emma was the foetal cell suspension as a multi-dimensional object with different kinds of empirical as well as experienced values. The foetal cell suspension is a liquid containing cells from aborted fetuses. What is used is a cell from the developing brain of 6–9 week old fetuses, with the sought-after property of being able to restore dopamine production in the adult, Parkinson-afflicted brain. Some other components are added to the cells in order to keep the cell tissue alive and 'fresh', while preventing further development and division of the cells.

The immediate value of the cells for the researchers that work with them in the laboratory is measured in cell survival (viability) and nerve growth (innervation) of the cells in the brain of the transplanted rats. For the researchers, it is a matter of making this value mobile (Rose 2007), from foetus to patient, via the laboratory (Wiszmg 2016). This value may even be said to relate to a certain economic value, since it has effects on the researchers' careers and an internal biomedical 'market',

even though formal commercial trade with these cells is prohibited, due to them being of human origin, rather than an invention.<sup>2</sup> Aspects – such as the age of the embryos, possible infectious contamination and the amount of surviving cells that each embryo can produce – determine the ultimate value of the foetal tissue. Another circumstance is that the demand for foetal material needed to carry out research and transplantations is greater than the supply; there are never enough aborted embryos available.

With the help of some value categories from moral and value philosophy and ethics, I will now address different values perceived of and attributed to the foetal cell suspension by those interviewed. Highly simplified, something that is *morally good* is usually attributed to humans or human actions, while a *natural good* is something that is seen as a property of objects.

Some different ways of making sense of the foetal cell suspension can be traced in the interview with James. His main task is the transplantation of the suspension to rats in order to evaluate the effect of the cells. A multi-layered discussion on the contents of the cell suspension evolves, spanning from its physical to its existential and symbolic content. This points to the kind of diversity in understanding and rendering of the cell suspension that I want to capture and discuss the implications of. It is clear that James does not have one, but many views of the foetal cell suspension. My first question concerns what James considers the cell suspension to consist of.

JAMES: I guess if I take it from a very physical point of view, it contains disassociated cells that we've collected from foetal tissue. And, you know, going up the scale in that way then it's essentially like a processed piece from abortion material. And, in one way if you think of it – if you were a patient enrolled in the procedure – then you'd see it as a kind of a hope. It's a hope to, you know, something that will modify your life, at least. If that's positive or negative, but you have the hope that it's positive, so, I guess it's kind of transformative. Depending on what point of view.

ANDRÉA: Of course. It has many dimensions, I guess?

JAMES: Yes! But I think for me when I see it or consider it, I just think of the cells and where they came from.

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2. See Directive 98/44/EC of the European Parliament and of the Council of 6 July 1998 on the legal protection of biotechnological inventions, here: <http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX%3A31998L0044> (accessed 29 July 2016).

When James and I discuss the contents of the foetal cell suspension, he acknowledges, in a sense, the values ascribed to it as both a moral and a natural good. We know that the tissue has therapeutic potential. This also adds an instrumental value (Schroeder 2016); James argues that its instrumental good as being therapeutically promising can be seen as a hope for a cure for the patient. This highlights a transition from a natural to a moral good.

This is, however, a two-faced potentiality. Not only has the cell suspension the possible capacity of curing Parkinson's disease in a person; its original foetal cells would have – if left to develop in utero – made a new human life possible. The two different potentialities could be seen as two kinds of inherent natural good of the foetal cell. If an embryo is aborted it cannot become a baby, but can theoretically be transplanted into a Parkinson patient. Either choice is mutually exclusive and can become the topic of an ethical debate. This, I argue, simultaneously makes the natural good of the cells into moral good, as well.

However, as the foetal cell per se (outside an embryo) would not exist as a proper object without human intervention, it is debatable whether the cell could possibly have natural value disconnected from a moral value at all. Since the existence of the cell suspension depends on human intervention, it seems to escape exact definition on the scale between human action and material object. Not only its constant state of transition, but also its high symbolic value as being transformative, adds to this elusive condition. I would argue that the idea of an intrinsic or inherent good of the foetal cells is a fallacy, since it is based on a projection of our human hopes, dreams and desires. So philosophically and theoretically, the inherent natural good is (in this case, at least) nothing more than an instrumental moral good in disguise.

Still, the idea of an inherent natural good in the foetal cells functions well for pointing out how different values of the cell suspension are perceived by the humans – in this case the biomedical researchers – who are interacting with it. The distinction between inherent natural good and instrumental moral good (no matter how impossible) also helps to visualize the transformative force of the cell suspension – material as well as symbolic. Not only does the perceived value of an object differ; the different knowledge and attributed value renders the object in *itself* different. Taking Parkinson's disease as an example; the knowledge about the disease is not the same for a patient as it is for a relative, researcher or for

a medical doctor, neither is the foetal material nor the subsequent cell suspension in themselves. This is a point that James also acknowledged.

The interview with Emma was different. We both seemed aware of the limits of each other's knowledge and philosophical viewpoints, but somehow we lacked the involvement or tools to enable new diffractions together, that is, to explicitly acknowledge the complex plurality of the foetal cell suspension. We rather, but in quite a dispassionate way, registered each other's expressions and opinions. The interview mainly traced some already existing diffractions of the cell suspension, and made them visible. Our difficulty in making progress in the conversation is palpable in the quote below concerning the material components and possible philosophical dimensions of the foetal cell suspension. I entered this theme by asking Emma what she considered the foetal cell suspension to consist of:

ANDRÉA: So then I'd just like to ask very openly, from your perspective, what this cell suspension consists of?

EMMA: Well, I ...

ANDRÉA: It's a tricky one! And you can answer whatever you feel like.

EMMA: I just see it as being living cells. – In short.

ANDRÉA: Yes, but when it comes to, I'm thinking purely materially, the substance surrounding it, the hibernation fluid and stuff like that. Is that something you think about, or do you think of it as purely cells?

EMMA: Yes I do. I really don't consider the other.

From here on, we did manage to advance a little further in our common analysis of the pluralities of the foetal cell suspension. However, we never really seemed to enter a sphere of conversation where the level of common analytical understanding or interest could be taken for granted or was a given. Later in the interview, Emma had clearly attained a picture of where my analytic interest resided and could therefore more readily answer my questions. However, this did not mean that she took an obvious interest in these issues herself, as we shall see further on.

### *The potential in the location of the foetal cell*

My idea was to understand if and how objects and experiences are produced plurally in the laboratory setting, thus problematizing the question of which knowledge that is valuable, to whom and in which ways.

In order to get a dialogue going on this plurality or multiplicity, I started a conversation with Emma on the potential of the foetal cells making contact in the new host brain and starting to produce dopamine. This is the mechanism that could help alleviate symptoms of Parkinson's disease. In this way, I tried to pursue my research interest in whether this potentiality could be said to be inherent in the cells, or is created in the laboratory: I think that the potentiality is there, of course, but if the cells were to develop without making contact with a brain, then something else would have happened to them.

EMMA: Yes, it would, exactly. Just as we have been using this kind of tissue to place in petri dishes. Then they develop into nerve cells at that point, and they don't have the ability, or well, they have lost that potential. Because then they have developed to nerve cells outside a patient's brain. [...]

ANDRÉA: But they have still fulfilled that potential, not in a patient or in a rat, but they still made these nerve cells.

EMMA: Yes, but they lost this entire ... no contact has been made between them.

ANDRÉA: No, of course not.

EMMA: So in that way they might not get the exact same properties.

The potentiality of the cells seems to change depending on context. While Emma and I expressed ourselves differently, it seems that we agreed that the potential of the cells was wasted when left to develop in petri dishes – even if I maintained that they had fulfilled their potential before it was lost. I argued that their potential or natural inherent good has been expressed. However, it is (as addressed above) debatable whether this potential can at all be regarded as natural, given the need for human intervention for it to be transferred from an aborted embryo to the brain of a Parkinson patient. James, on the other hand asserted that the potential must be fulfilled in a certain way and in a certain location in order to be valid. Thus, the only value of the cells is that of their instrumental moral good. The cells are solely a means to an end. In a sense, this is the basis of action for all biomedical research using living tissue.

### *The cells, the babies and the patients*

Emma tells me that she would later like to work in an assisted reproductive technique clinic (ART), in order to establish a kind of 'balance' for all the aborted embryos she has handled. Ethnologist Susanne Lundin

has reported about a female scientist working with creating stem cell lines from aborted fetuses, who did not find her work problematic until she became pregnant herself (2012: 22). Emma, on the other hand, did not find the work with foetal cells in itself emotionally disturbing during her own pregnancies. Nevertheless, a sense of guilt seems to have been produced in her, resulting in a desire to make amends at a later date. However, we need to be careful when drawing conclusions about the inner motivations of our participants. The only thing that I can be sure of, is that Emma does express this desire in the interview, and that it makes her diffract the foetal cell suspension somewhat differently than James does:

ANDRÉA: I just feel it would be strange not to address it, because I think it must affect you both [Emma as well as James], in your professional roles in some way, how you think of it, how you talk about it?

EMMA: Yes, and I kind of feel that after this project, that I would love to work in IVF [in vitro fertilization].

ANDRÉA: Yes?

EMMA: And in some way, I feel that I want to, maybe, be on 'the other side' for a bit! To actually help those who want kids (laughs), instead of those who want to remove them all the time. You just feel that it's so many, I don't know, I have been working with this now for, is it five, six years, with embryos. I mean how many aborted fetuses haven't I handled?

It can be argued that it is the instrumental framing and 'industrial' use of the embryos that makes Emma experience the demands and expectations of her role as a woman and a mother in stark contrast to the demands and logics of her work. She seems to experience the different values (natural or moral) of the foetal cell suspension to be in conflict. Someone without Emma's experiences of being a woman, mother and biomedical researcher, someone outside these intersecting categories, may well have had the same opinion, even if they are not based on the same experiences. Most important for the purpose of this chapter, however, is that Emma's reasoning opens up for thinking about aborted embryos as potential children. Not these specific embryos – since the decision of these women to have an abortion was in no way controlled by Emma or by the clinical trials – but embryos in general.

The potential of the foetal cells to develop into an embryo and subsequently a baby, provided that they stay inside a womb of a woman, is

another kind of inherent good of the cells. It can be regarded as a moral good, as well as a natural good. Since the foetal cells do not need human intervention in order to develop into an embryo in utero, this potential seems more obviously a natural good, than the potential of the cells to treat or cure Parkinson's disease.

This way of diffracting the embryo into an object with different biological and therapeutic potentials makes it into, what can be described as a 'bio-object' with transgressive qualities that challenge notions of life, death, of the biological and the mechanical, and of what is ethically defensible, possible and what is not (Holmberg & Ideland 2012).

### *The social sex system of humanness*

These multiple meanings of what the embryo is, comes to the fore now and then in the interviews. James tells me that the instances he recalled as the most unpleasant ones in embryo dissection occurred when the embryos had developed a bit too far and you could define – and here he stresses – their 'physical sex'. It seems like he wants to make sure that I understand that, to him, social sex or gender does not necessarily correlate with biological sex. Neither does he view the biological, or physical sex, as essential. James explained: 'When it's [the embryo] you know, older age and you can determine like physical sex and things like that.' Interestingly, Emma, too, mentions the ability to distinguish the sex of the embryo as an instance when dissecting becomes uncomfortable. She elaborates a bit more:

But when we did experimental [research] earlier, we accepted more of 'well we don't really know what the ultra sound said, but we just got something here now', and then we said 'ok, but let's take it and see if we can use it'. And then it comes something that is way, *way* too old, and you can almost see the sex and ... Well you know, then it's very unpleasant I think, since I'm not used to that. And I mean I sit there with my small instruments, these are small embryos, that you are supposed to dissect – suddenly you get something this big that I can't even use my tools, instruments, on.

Sociologist Bruno Latour has argued that it is only when things break or stop working, or when results are inconsistent, that it is necessary to open the opaque 'black box' of science (1999: 184f.). It is not until then that the mechanics, or the practice that we habitually engage in, becomes visible or problematic for us. The instance when the embryo all of a sudden is too large to dissect with the usual instruments is an exam-



ple of this unveiling. The situation works as a lens making the foetal material diffract in otherwise invisible ways.

For Emma and James to be able to determine the sex of the embryo means that it has developed further than it should have for their purposes and must thus be discarded for use in the clinical trial. But what they say also implies that (physical) sex is a highly important marker for regarding an embryo as a human being. In my view, it is also illustrative of the extent to which anthropocentrism – the norms and hierarchy that set humans apart from other living beings – rests upon the binary sex/gender system. Although we humans extend this duality to the rest of the animal kingdom, I am not sure my participants would have reacted in the same way if they were dissecting pig embryos. I cannot imagine them feeling a sudden unease on the basis of discovering that the pig embryo could have been a sow or a boar. But then again, they might well have.

When the physical sex of the embryo is distinguishable, it affects how the foetus is diffracted and would subsequently also affect the diffraction of the foetal cell suspension. James' remark concerning this highlights the humanness of the embryo even more, since it implies that it may also have a gender – a *social sex*, not necessarily correlating with the physical sex. We (humans) do not normally attribute gender to (other) animals. The remark is an extension of the insight that the cells come from embryos that might have been babies, which would have been human beings. Thus, James and Emma's unease at discovering the over-development of the embryos can be seen in the light of the inherent (moral) good of the cells to create human life.

### *Professional roles, conceptual mix-ups*

In addition to the entangled differences – or intersections – between James, Emma and myself concerning the diffraction of the foetal cell suspension, there seem to be professional and role based differences within the biomedical project that they are involved in. Consequently the idea of the foetus and the foetal cell suspension is diffracted and becomes plural. This is of course highly relevant for how knowledge and objects are produced. I asked James and Emma where they see the largest discrepancies in the project concerning what to call the foetal material, and if its name changes even if it keeps its material properties. They both stated a number of instances of such discrepancies and began to

elaborate on why it may be so. Their explanations related to differences in professional practice, where the greatest difference occurred between staff who were in contact with the foetus as an entity, and those who were not. In addition, staff at the abortion clinics have a relation to the aborting women, which influences the language used and the material reference points that are made.

ANDRÉA: Do you follow me; that it kind of changes names, depending on who's talking, and it doesn't have to be just the tissue, it can be something else.

EMMA: Well, yeah it might actually change, as it goes. I feel that, sometimes I might call it more what it really is. I might say 'the aborting women' and 'embryos', more than maybe the others do at the meetings.

ANDRÉA: What roles do the others that you think of, have?

EMMA: I think of another colleague for example, he might call it 'tissue' and 'donors'. I mean you keep it a bit more ... The people at the abortion clinic, they don't say ... they are 'patients', they see the patients more clearly.

ANDRÉA: What do they themselves call the tissue when you come to pick it up?

EMMA: They don't say 'tissue'. They would say 'embryos', there.

ANDRÉA: So it's a bit more ...

EMMA: ... what it is at the time, kind of.

James, on the other hand, found that this conceptual mix-up did not always depend on contact or not with the fetus. He said that he too sometimes would make such mis-references. Thus, the different terms that initially referred to different states of processing of the foetal material are often used interchangeably. However, it may make the staff draw faulty conclusions about the availability of the foetal tissue, since not all aborted tissue is actually usable.

JAMES: Usually I'd say 'the tissue piece', but it's an embryo. You know? I think that's a pretty clear discrepancy. I might call it one thing, but in actuality I'm going to be using specific incorrect language. It'll be something else. You'd say tissue or something, rather than like: embryo. Some people might say 'products of conception'. Or 'abortion material' or whatever, you know. We usually say like 'tissue' or 'embryo', and it doesn't trigger as much sensitivity, if you can say that. So that's kind of an example.

ANDRÉA: That's a clear example as I see it.

JAMES: So I guess I'll usually refer ... I mean like today we got these two patients who consented, in that case it is *patients who consent*, you know, and some people will go 'okay, well there's two patients; we'll have two embryos'.

There is thus a re-occurring mix-up between concepts such as donation of aborted fetus, collection of it, an embryo, the dissected tissue, and their material referents, which seems to be influenced both by personal and professional practice, as well as national and cultural attitudes toward abortion.<sup>3</sup> Phrasing and interchangeable use of different concepts is, in short, highly dependent on experience and expectations. Such discrepancies in how the cell suspension is rendered occur between researchers and patients but also as we can see here, among different researchers. Not only is the value and meaning of the cell suspension fleeting; so are the conceptual boundaries of the material needed to create the suspension. There seem to be no exact and solid borders between the aborted fetus, the dissected tissue piece containing the brain cells, the isolated cells themselves and the final cell suspension.

James also told me about how a colleague of his mixes up what it means to have received, on the one hand, a woman's consent to donate the embryo she is about to abort, and on the other hand, the actual embryo to work with in the laboratory. Consent does not automatically mean that the foetal material will be usable for the scientists. It may be too old and too far developed or too damaged for their purposes. Moreover, the woman may still change her mind and withdraw her consent. Still, this colleague occasionally uses 'consent' synonymously with 'embryo'. The colleague has no prior experience in collecting and dissecting embryos, or making the cell suspension, but is specialized in transplanting the cell suspension to rats. This may, according to James, be part of the explanation of why the colleague continues to mix up the concepts and what they entail expectation-wise. This conceptual mix-up also tells us something about value. It seems that the expected usefulness of the foetal material to a specific profession, makes people favour one concept over another. For those who, as this colleague, transplant cells to rats or patients, the value lies in the possibility to have a suspension to transplant. There is no point for them in making a distinction between consent and embryo, since – as far as they are concerned – an embryo is

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3. Differences in phrasing, depending on for example national research setting, were addressed by James in our conversations, but will not be referred to in ad verbum or quoted here in order to protect the anonymity of others.

equal to a realized consent, when it reaches their hands. Consent is, to them, an instrumental good on the path towards an aborted embryo and a manufactured cell suspension.

### Searching together or apart?

I will now leave the analysis of the plurality of the foetal cell suspension and turn to a discussion of if and how the diffractive approach worked to enable the creation of new knowledge in the interviews. We will look closer at the ways in which the approach contributed to a broader and more plural understanding of the foetal cell suspension. The chapter will then conclude with a discussion on how a diffractive approach may be valuable for interdisciplinary research in general, and in particular when biomedicine and neurology are involved.

So, when did we search together and when did we instead search apart? And what consequences did the different modes have for the knowledge brought forth in the interviews? Emma and I projected our respective and different views of the foetal cell suspension onto a common lens – the situation of the interview itself – in order to reach an understanding of the other's views. James and I, instead, first found a common understanding of each other's views of the foetal cell, and then used that common picture as a lens from which a spectrum of other possible cell suspensions were diffracted. We thus spent a lot of time looking for our *common* limits and ways to transgress them. We seemed to align more easily than Emma and I did, and it was easier to exchange and enable new views together around the common topic. Thus, James seemed to have a more flexible way of viewing the foetal cell suspension as plural. He helped me see how the cell suspension was understood and valued differently in different settings of the trial, and how each step was connected, not only to the bringing of the cell into existence, but also to the evidence and legitimacy production around it; that is, what made it 'work'.

I was open about my views and understandings of their knowledge production. James did try to see the issues from my point of view, which was a philosophical and knowledge-problematizing outlook. Even if he did not share my view entirely about the potentiality of the foetal cells, he tried hard to explain the logics of their research so that it made sense to me. He was openly curious about my view and seemed genuinely excited by my way of asking questions.

JAMES: The immunosuppression, I think that's probably the only or the biggest thing, because again, it's a bit of an unknown, you know? You inject it in the belly [of the rats] and then it kind of protects the brain. It's a bit of an unknown process but I think it's kind of crucial. If we had a transplant with no survival, the first question I would get would be: 'well did they get the drugs fully?' So, I think they're kind of essential for preserving or maintaining the integrity of the cells, after transplanting them.

ANDRÉA: But you would still say that, of course you cannot see the drugs present in the brain, but would you still say – '[be]cause they are so crucial for the survival of the cells' – that they are something different than the cells?

JAMES: Transformative?

ANDRÉA: Yes.

JAMES: Yes, it's a different part of the process with the cells, for sure. I think of it as if you make a sand castle, so the cells are the sand castle? And then, the drug is just kind of, to put a barrier to stop the waves from coming, you know?

ANDRÉA: Yes.

JAMES: [Be]cause if you let the waves come, the sand castle falls down and you won't have any neurons, so I guess in that kind of physical representation of it, then they're very different entities. Physically but also functionally.

ANDRÉA: You are painting such nice pictures to me [laughing], I'm getting this visual.

JAMES: I'm kind of making it make sense to myself too.

ANDRÉA: No, but it's good because it helps me understand these things as well. I don't know if you ever get these kinds of questions?

JAMES: No, I don't, so it's kind of fun!

Nevertheless, I sometimes instead chose to talk of the foetal cell suspension in the same way as they are expected to do to in their research environment, that is, either from a strictly cell biological view, or from a broader medical perspective within what can be called an evidence based project. I did this, either by repeating what they had told me about the workings and logics of a practice of theirs, or by trying to draw a conclusion inside their perspectives, based on a piece of information given to me by them in the interview situation or earlier. I did this in order to establish a common base from which to move forward. I have reason to believe that my participants also tried their best to establish such a common base.

In the following section, Emma and I discussed the risks and possible benefits for a Parkinson patient in receiving a cell transplant.

ANDRÉA: I start thinking that it is a bit different then from, I mean that as you say, it is quite a serious operation that is to be done – in very ill patients – but maybe nonetheless with not as severe symptoms. I mean with other kinds of big operations you might – at least as a clinician or doctor – when it comes to other diseases, whatever it might be really, that if someone has serious heart problems you might say that ‘ok but it is worth taking this great risk and make a transplantation ...’

EMMA: You have a twenty percent chance to be cured, but that twenty, exactly ...

ANDRÉA: Is better than ...

EMMA: Is better than, maybe, yes.

ANDRÉA: But in this particular case it’s special.

EMMA: But in this case it’s not, because maybe ... Let’s say that there’s a risk that they develop dyskinesia<sup>4</sup> or something due to the transplant, so that you kind of, might create severe symptoms instead of relief. I mean, that just can’t happen, then it’s better that this patient is medicated.

I adapted to the logics of Emma’s research, by trying to show her that I understood the calculation of risk that they needed to do in order to legitimize the choice of patients for foetal cell transplantation.

In this next extract, James and I talked about the relation between data and evidence. The topic in itself is, of course, very theory-of-science oriented. However, I showed that I tried to enter ‘his’ perspective and understand the relation in his specific case and the problems and possibilities it may cause.

ANDRÉA: That’s really interesting, because this really highlights the relation between data and evidence in a sense. You have the large data set on the patients that you have produced during the trials, and then also, in relation to the end goal, so I think it’s really interesting.

JAMES: And we’ve generated a lot of, I guess evidence, and from my part then with the different tissue. In what ways we collected the tissue, through medical abortions or surgical abortions and then we’ve also generated a lot of evidence which [does] not necessarily comply with the outcome, but with the variability we discussed in quality, and that’s why I said even if it doesn’t go to transplanta-

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4. ‘Dyskinesia is a difficulty or distortion in performing voluntary movements’ (<https://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?dyskinesia>, accessed 25 June 2017).

tion I think that it's not necessarily unsuccessful. Because we've very extensively proven that if you try this in many countries for a long time, this is what you get. And that in itself is a strong body of evidence as well.

The two latter excerpts above are examples of how I tried to search, together with Emma and James, for the premises for knowledge of the foetal cell suspension that their profession requires. It can be argued that this, for a moment, made us more alike. Asking direct questions on knowledge and object production, the way I did in the initial excerpt of this section is, on the other hand, a way of making a difference between them and myself.

When I entered their perspectives, which arguably made us 'more alike', as in the two latter excerpts, this can be regarded as a way of enabling better diffractions later, from a common ground – just as James often took my approach into account during the interview. In a sense, it can be viewed as my way of looking for the right type, strength or grinding of a lens – which would here be their understanding of a phenomenon – in order to later be able to achieve as much diffraction as possible. If it could be established that I understood their point of departure in their reasoning, they would perhaps trust me more as a guide to a philosophical detour, which may then result in a greater conceptual plurality in the ideas concerning foetal cell suspension in our conversation.

James and I seemed to agree – more often than Emma and I did – that our respective different diffractions of the foetal cell suspension could indeed be just one side of the truth. Still, we just as often in a manner of respect kept to our initial stand points. Whether or not we were sometimes just being courteous with each other in order to keep peace on the issue, I dare not say. However, I would argue that we *did* diffract to a view of the plurality of the foetal cell suspension, by taking the realities we presented to each other seriously and acknowledging them without abandoning our individual points of departure and without aligning fully.

JAMES: Do we modify the foetal cells, or their kind of function or ability? In that way, no. Because I think they can still do the desired characteristics, if I can put it [that way], so they can still, generate dopamine neurons, they can still release dopamine, they can still innervate and go certain areas and survive in the brain. And those kinds of qualities and characteristics we want in a transplantation setting. So again, there's a lot where we don't modify that, but in saying that, if they were left where they were, I mean, there'd be a lot more of them and they'll do it a bit more efficiently, but I don't think we negatively affect it.

ANDRÉA: No. But the function of the cells is ...

JAMES: Maintained. I think so.

As to the conversation between Emma and myself – was it more a case of us bonding in a *different* way, rather than us bonding *less* than James and I? Did our way of finding common ground and common understanding of the scientific processes use a different – and on the surface ‘non-scientific’ – language, which I did not discover at first? Yes, this might actually have been the case. Even if James and I clearly advanced further in our discussion of knowledge connected to the creation and use of the foetal cell suspension, which was what I set out to do, Emma and I instead found a common understanding in discussions of the problems of administration and of the planning of a large multi-site trial.

### Conclusions: disagreement in respect

What is the usefulness of a diffractive approach when aiming to understand how scientists work and talk about their practice? It may contribute to developing what I, in the introduction to this chapter, called ‘science’s understanding of/engagement with knowledge’. The diffractive approach may help visualize the still-not-explicit, as well as the tactile knowledge produced in scientific processes, including those within neurology and biomedicine. A focus on tracking diffractive processes is a way of being responsible for the knowledge brought forth and for the different values attributed to that knowledge. It is a way of accounting for the produced differences and the plurality in objects and artifacts, knowledge, values and experiences, and the different effects they may have on people’s lives. As I have tried to show above, a diffractive approach may be especially fruitful within neurological research, since the scientific objects involved – such as the foetal cell suspension or the human brain – are suggestive and multiple. They are at once concrete physical objects (however in varying and changing stages) and abstract surfaces on which dreams, hopes, values and fantasies of life, death and potential are projected. A diffractive approach can help visualize how this happens and by which logic, by allowing and facilitating diversity even at the physical level.

I also think that a diffractive approach could be valuable within interdisciplinary research, since it allows researchers with different epistemological points of departure to assess new knowledge and to identify the potential and force it may have. It may also help to illuminate where



and why misunderstandings and misinterpretations between different disciplines occur. As a best-case scenario, it could lead us to acknowledge different expectations and common (but plural) anticipation of research goals and aims in inter- and cross-disciplinary research projects. A willingness to participate, to contribute and to share has an important place in interdisciplinary work and research. It requires openness and a humble attitude towards the other.

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Parkinson's disease is a neurodegenerative affliction to which researchers have long striven to find a cure. The human embryo is a source of vital cells used in regenerative medicine, as well as a powerful symbol of life. Using foetal cells from aborted embryos for transplantation to the brains of Parkinson patients is an avenue that has been explored by neuroscientists on and off for the last thirty years. This ethnological compilation thesis follows a national branch of a foetal cell transplantation trial through successes as well as challenges in processing foetal material into an effective, transplantable cell suspension. The cell suspension is conceptualized as a bio-object, and explored as something that produces new knowledge, emotions and logistical and ethical negotiations. These products are beyond the scope of the trial and biomedical research in general, but they do nonetheless interact with and affect society at large.

New biomedical inventions and forms of therapies transgress the limits of life and death and the boundaries of individuals, as well as between species. Such cultural reordering challenges researchers, health care professionals as well patients on a daily basis. Exploring the intersection between instruction and practice, nature and culture as well as between science and ritual, this thesis contributes to a broader understanding of cultural and material conditions of knowledge production. It also offers a methodological elaboration of how a diffractive approach may be fruitful in ethnographic research, when trying to reconcile epistemological differences in cross-disciplinary endeavours.

The thesis is itself a product of multidisciplinary cooperation, in which the researcher is affiliated with the milieus the Department of Art and Cultural Sciences and the Basal Ganglia Disorders Linnaeus Consortium (Bagadilico) of the Medical Faculty, both at Lund University, as well as the Learning and Media Technology (LET) Studio at Gothenburg University.

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