

A Cultural Account of Organ Transplantation in Ontario, Canada

Adrian Joseph Bertoli

Supervisor:

Per Kristian Hilden

University of Oslo

Faculty of Medicine

Institute of General Practice and Community Medicine

Section for International Health

June 2009



Thesis submitted as a part of the

Master of Philosophy Degree in International Community Health

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1. Acknowledgments

First and foremost I would like to acknowledge and thank the participants. Thank you for opening your homes, your hearts and your minds and for sharing your stories. I learned so much from you all, much more than can be expressed within these pages.

I would also like to thank ‘The Ontario Donation & Transplantation Association of Canada’ for their financial support.

To my supervisor, Per Kristian Hilden, thank you for your guidance, insights, comments and patience. Thank you for being there, for me and with me, on this journey. Thank you to all the professors, coordinators, and classmates at the Institute of General Practice and Community Medicine for a great two years. I wish you all the best in your future endeavours.

Furthermore, I would like to thank my family and friends back in Ontario, Canada. Thank you for making me feel like I have never left. A special thanks to Maria. This would not have been possible without you.

To every single person, who for various reasons have not been mentioned here, I am forever grateful for help during the process of researching and writing my thesis.

2. Abstract

Organ donation and transplantation is about bodies and body parts. It is about life, death, and the range of social experiences and relationships that fill the spaces between the beginning and end of a life. The study is a qualitative exploration of organ transplantation as a cultural phenomenon. The study draws heavily on interview material from transplant recipients and those close to them, in Ontario, Canada. An interpretation will be made by linking recipients' statements, symbols, etc. in order to get at possible meanings and present a cultural account of organ transplantation. It will look at the understandings of the body and its organs present among people and society, and see how they allow for organs to take on a life of their own. This organ then becomes a party to the lives of transplant recipients, bringing with it a social force; the origin of which is grounded in our everyday understanding of the interrelatedness of life. We will see how this 'animated' organ comes with obligations, as part of the circle of gift exchange, upon which organ donation and transplantation is dependent on. We will then look at recipients' attempts to fulfil this obligation, what will be suggested is a type of social burial. This need to put the 'animated' organ to rest might at times conflict with donor kin's desire to have a memory of their loved one live on. Zombies and ghosts will be examined as widely circulating representations of inappropriate death in an attempt to give justice to some of the experiences of recipients. Cellular memory will be presented at the end as an attempt to bridge some of the mysterious and scientific aspects of organ transplantation.

3. Introduction and background

Within a society, there are biomedical and cultural understandings to organ transplantation. Biomedicine posits organ transplantation as a technical, therapeutic procedure in which the body is treated as a series of replaceable parts (Joralemon, 1995). However, organ transplantation also interacts with culturally shaped notions of what it means to be human. Phenomena such as donor memorials, the concept of the “gift of life”, and popular cultural considerations in the media [e.g. *The Simpsons* (TV), *The Eye* (movie), *A Change of Heart* (novel)] indicate that the social relevance of the body to the self does not disappear with the declaration of brain death and that organs remain meaningfully connected to the self through the gift of life. Death is treated as though some quality of the person survives. This may connect the donor and recipient through organs which may carry metaphorical (e.g. identity) or various types of symbolic meanings (e.g. the heart and virtues such as love and compassion that it represents) or both. Although biomedicine and culture may be analytically distinguished and are commonly separated, they are bound together and intersect in society in many ways. Also, biomedicine exists within a specific cultural and historic setting.

A point where this intersection comes to light in organ donation is the recent advent of visible and non-vital organ transplants. An example would be the successful facial transplant in France, which required a great deal of technology and also raised issues of identity, individuality, and kinship (Carosella 2006). Further cause to examine notions of identity, citizenship and worth are the recent advent of internet donor matching services in which would-be recipients post profiles and pleas for organs (Kondro 2005). But we can also see this interconnectedness when biomedicine and culture clash in areas as mundane and supposedly non-controversial as public safety. The Government of Canada’s recent decision to place men who have sex with men in the group of high risk individuals excluded from organ donation is one example. Here exclusion based on the principle of public safety maps onto social identity categories to raise highly charged questions of worth.

Organ donation and transplantation is about bodies and body parts. It is also about life, death, and the range of social experiences and relationships that fill the spaces between the beginning and end of a life. As a procedure, organ transplantation perforates these bodies physically (a new organ), pharmacologically (powerful anti-rejection drugs), and socially (rules governing behaviour and lifestyle set by medical institutions). This may lead individuals to reflect on notions of identity, citizenship and worth in reference to organ transplantation. This study is a qualitative exploration of the tensions present in the lives of transplant recipients and those around them as they navigate a world of incompatible, unequal, and competing understandings about the body, its parts, and what happens to them after death and transplantation.

After looking at a detailed case study in chapter 6 as an introduction to the analysis, we will begin in chapter 7 by examining the various ways of analyzing and thinking of and about the body. The dominant discourse in Canada, and that which transplant's success depends upon is dualism, the separation of body and mind. We will briefly trace its origins, and how it is applied to – and what purpose it serves organ donation and transplantation. Although this is the dominant discourse, there is evidence that it is not what the participants in the study understand of what constitutes a 'body'. There are other belief systems that take a more holistic or monistic approach that emphasize the relationship of parts to the whole. These tend to view the 'person' as "inextricably tied to the sheer materiality of the body and its parts (Rabinow as quoted in Joralemon, 1995: 339)." We will suggest later that the 'person' (i.e. donor) is also tied to the sheer 'social materiality' of its life. This social materiality comes from the inherently social nature and interrelatedness of life; that is of any life-in-particular.

Chapter 8 will then look at how these 'other' understandings allow for organs to have social lives. These social lives appear to survive biomedical attempts to reduce organs to pieces of machinery and present themselves in the form of a third party in the recipients' relationships with friends and family. The recipient is now looked at as 2-persons-in-1, as it were. The organs appear to come 'animate' with a social force, pushing through death and presenting this 'other' person, regardless of participants' understandings. The force behind this animated

organ comes from, in my material, the participants' everyday understanding of the social nature of life and how it lives on after death.

Chapter 9 will look at exactly what the 'social materiality' of a donor is made up of. It is their 'social baggage', all those characteristics that make us human and that are remembered by someone (or anyone) after death. This social baggage gives organs identity claims and presents itself through an organ's ability to acquire metonymic functions.

In Chapter 10 we will see how these identity claims mean that organs come with rights and responsibilities. It is evident in recipients' desires to 'do something' with their organs and 'new' lives, as a way of repaying the donor, their organ and their surviving kin. This notion is further fuelled by organ donation and transplantation making use of gift rhetoric to promote it. But as we will see, the gift exchange rhetoric is not without its problems. Organ donation is presented as an anonymous, altruistic act. Yet like any act of giving, there is a sense of obligation and expectation to reciprocate. The act of 'doing something' we will argue is an attempt to 'put to rest' this social force that comes with and animates the organ, and fulfil a recipient's sense of obligation.

After that we will turn our attention to the incompatible needs of recipients and surviving donor kin in chapter 11. Burials are employed in order to put to rest safely this social life force and there is no way that looking at transplanted organs as 'just tissue' can do this. Rather, an 'energy' or 'force', with incorporated obligations presents itself through the organ. We will see that the participants attempt to attenuate this force by putting it to use through a processes range of activities such as being sensitive towards cravings, memorializing the donor, and volunteerism related to organ donation. These processes amount to a social burial, a way to find closure or what others might describe as incorporation. But this runs counter to surviving donor kin's understanding that their loved one may 'live on' inside the recipient.

The final section will look at organ transplantation in relation to some widely circulated representations of non-conventional or inappropriate social death such as zombies, and ghosts in order to de-naturalize and 'de-technify' transplantation in the hopes of adding to the insight that can be drawn upon in educating patients, donors and donor kin, and recipients, and to counter the biomedical perspective's dominance in that arena. The study will then conclude with a presentation of cell memory, an idea that will be used to attempt to bridge the mysterious to the scientific.

4. Literature on organ transplantation

The bodies of literature tend to cluster into several categories each having their moment in the spotlight depending upon the (social) zeitgeist of the societies within which these debates take place. Organ transplantation literature can be arranged on a spectrum from clinical realities (problems in medicine) to cultural debates (problems of medicine). Literature on organ donation and transplantation is clustered into groups from the technical to the cultural. The technical aspects of organ donation are vast and over represented and will not be addressed in this review. The focus is on cultural debates of organ donation and transplantation. In organ donation literature, studies often focus on the low rates in organ donation among the public, emphasizing the difference between groups, and possible reasons why. There is some literature that looks at donor families' experiences (Sharp, 2001) but this group is under represented. Human rights and legal debates centre around the illegal trafficking and trading of human organs (Scheper-Hughes, 2000), and debates about organ donation and procurement policies (Arnold, 2005).

Literature investigating the social aspects of organ donation has focused on among other things; the disparity in donation rates between various ethnic minority groups and the general population. In the United States the bulk of the research is on the low rates of organ donation among the African American population (Boulware et al, 2002), and to a lesser extent to Native American (Fahrenwald & Stabnow, 2005). In Canada there has been research into the low rates of organ donation seen among Indo-Canadians (Molzahn et al, 2005), and Chinese Canadians (Molzahn et al, 2005). The studies all seem to have religious/spiritual beliefs as a common thread partially explaining low rates of donation. In the case of Native Americans, geographic location was examined as a potential barrier, but in the context of receiving a kidney transplantation (Gill & Johnston, 2007).

The journal *Medical Anthropology Quarterly* devoted an articles and commentaries section to cultural perspectives to organ transplantation in 1995. In the issue, Joralemon analyzes the

values behind organ transplantation of altruism and individual rights in the United States of America (U.S.A.) as the ideological equivalents of immunosuppressant drugs. These he argues, are needed to inhibit cultural rejection of transplantation and its views on the body, which differ from common understandings (Lock & Scheper-Hughes, 1998). Sharp looks at the transformative experience of recipients in the U.S.A. as they try to restructure their sense of self while having to manage conflicting cultural values surrounding death and dying and a transplant ideology rife with contradictions (Lock, 1995). Lock (1995) comments on the contradictions rife in the transplant world that inevitably arise from mixing self and other, a long standing dichotomy. This argument is similar to one I will present later, one I will make use of. The biomedical transplant world attempts to naturalize this technology, a process that has caused little public furor. These self/other and culture/nature contradictions are further confounded when the donor is brought back into the debate. Lock points the way forward, saying that what is needed is to “show not only what hybrids signify for the social and political order, but also how these contests are enacted in the everyday lives of those most deeply involved with the new technologies (392-393).” This is a need I will attempt to meet in this thesis. Koenig and Hogle (1995) comment on the Joralemon and Sharp articles and offer up some questions, to come out of their critique of the articles, for further study. There is a need to understand more about how and why receiving a body part evokes feelings of kinship, how recipients felt about their "illness" or bodies before receiving the "new" organ and how recipients feel about the loss of their own body part.

A recent debate showing where risk maps onto social categories is the Government of Canada's to place MSM on the list of 'high risk' donors. This discourse about regulations and social categories versus conceptualizations and (regulations) of safety issues was the original point of interest of entry into the topic of organ transplantation as cultural phenomenon. This decision is important to forming the account for what type of phenomenon we are dealing with.

A current account of North American medical anthropology is Emily Martin's *Flexible Bodies* (1994), in which she traces America's changing ideas about health and immunity since the 1940's. She shows how the concept of flexibility is influencing the way we think about

and conceptualize everything from the immune system to the corporate world and warns that we may be approaching an era of social Darwinism. It demonstrates how the organization of capitalist society provides the images and language with which we understand and describe the body. In the book she describes an emerging conception of the body not as a set of mechanical parts, but as a complex non-linear system (in which the body is in constant motion in relation to its environment). This could have a range of implications for many biomedical practices in which science and culture clash, including organ transplantation. It is only by better understanding the links between medicine, science, health, and society can we hope to avoid this approaching social Darwinism, in which certain categories of people will be left out.

What a review of the literature demonstrates is that organ donation and transplantation as a field is complex, with issues ranging from the biomedical/technological to the cultural/anthropological. The biomedical end of the spectrum is overrepresented in the literature, while as one makes their way through more legal/ethical issues to more cultural ones, the scope of literature diminishes. It is only more recently that more social issues related to organ donation have garnered attention. Lock (1995) pointed out that the idea of organ transplant technology has been accepted into society with little opposition or public furor. It is therefore a subject still worthy of investigation, as has been demonstrated, there are many topic left under-represented.

5. Methodology

5.1 Rationale for the study

These debates about broader political issues surrounding organ donation fit into the framework of international community health in many ways. Firstly, governments set the rules that directly affect the health of populations, making health a political issue. The formation of various social identities can be facilitated and reinforced by a mix of government public health policies and cultural norms (Weiss 2003). Secondly, although organ donation is a relatively new and Western technology, with the spread of globalization its practices and technologies follow. Many issues that are relevant to our societies now, such as equity of access to health services, will soon be on the door steps of more developing countries.

Organ transplantation is often seen as the pinnacle of biomedical triumph over culture, but its advent has given rise to a self-made shortage of available organs (Lock 1995), to which there is no easy solution. The problem is only getting worse and technology seems to have reached its limits in that transplantation is dependent upon a stream of available donor organs. So too in Canada our attention turns to the social, cultural and legal barriers to organ donation. Barriers studied in Canada include religious/spiritual beliefs, a lack of awareness towards organ donation, mistrust in the medical system (Molzahn 2005) and expressed versus presumed consent for donation (Arnold 2005). However, little is known on the ways in which cultural and biomedical understandings of organ transplantation interact on a personal level in a Canadian context. Also, public, media, and promotional portrayals of organ donation and transplantation focus on acts of altruism, and extreme examples like success stories with happy recipients doing well or when things going tragically wrong, like infants dying while waiting for a matching organ to become available. What are missing are the daily struggles of those attached to organ donation and transplantation. The stories in the middle, involving everyday issues, are underrepresented in both the media and in social and medical research literature.

The plausibility of the study became apparent at the HeartLinks' (a heart transplant support group) Christmas party, where I spoke to a small group of ladies who were heart recipients and they spoke of how little even very close family understand transplant and its effects. They mentioned how their families expected them to be back to 'normal' and didn't realize how much of a rollercoaster life can be, with energy levels varying widely. Another woman with whom I spoke told me how at various points in her illness and life post-transplant her own mother said she couldn't recognize her. Her mother described her as blue, yellow, or green in the face. She then suggested that a good title for a thesis would be "The Many Faces of Transplant" to emphasize just how complex it is. If this happens with close family, how much can the rest of us really know about the ins-and-outs of life post-transplant? In the media, recipients are portrayed as happy, energetic people doing incredible things in society. News stories focus on either the positive affects and changes that result from transplant or the heartbreaking struggles to find suitable donors while innocent 'victims' die from a 'scarcity' of organs. We rarely get a glimpse behind the scenes at what happens in between these extremes. It is these glimpses that this study hopes to capture, present and give an interpretation on, to bring them into the light of day for all to see.

5.2 Objectives: Pre-fieldwork

As these objectives are the ones I based my interview guide (Appendix 2) upon, and framed my initial reading and analysis of the materials, they are presented here to show the reader the origins of this study.

Primary objective:

- Generate new knowledge about organ transplantation in Canada as a cultural phenomenon from the perspectives of those personally involved.

Secondary objectives:

- Understand how the people that are involved with organ transplantation view themselves and the procedure, and how the rest of society views them.
- Understand how people involved in organ transplantation reflect on notions of self and social identity, and biological citizenship.
- Understand whether and how people ascribe different types of symbolic meanings to various organs.
- Explore to see if any claims to rights and worth follow from being a member of a transplant community. Transplant community in the context of this study refers to recipients, their close family, and donor kin.

The issues being investigated will add to the pool of knowledge aimed at improving organ donation and transplantation, from a personal level to policy.

5.3 Fields of inquiry & research questions: Pre-fieldwork

In order to shed light on the original objectives, I set out to focus investigation on three primary fields or themes.

Self & Self Identity: is the private, subjective sense of self. It is the self reflections of those involved in organ donation and their notions on bodily integrity and continuity of the self in time. Self-identity may play a role in determining whether or not recipients reflect on the identities of donors or have difficulty incorporating new organs into their self-image. How then, are these reflections expressed through the lived experiences of those personally involved in organ donation?

Personhood and Social Identity: is the cultural construction of what a full, integrated person is and how donor identities are expressed publicly. The technologies present in society are part of this cultural construction. How then, do the people that make use of these technologies view themselves and the technologies, and how does the rest of society view them? Do

people involved in organ donation reflect on notions of identity and citizenship and ascribe different types of symbolic meanings for various organs?

Biosociality (Rabinow, 1996): is the notion that individual and collective identities are dependent upon scientific constructions, forms part of this field. These identities may take on the form of the third field of inquiry, that of:

Biological Citizenship (Rose, 2005): is the view of organ donation and transplantation as a community of donors and recipients and the rights and responsibilities this puts on the state. It consists of individuals making claims to entitlements from the state, based on biology or a shared identity of “transplant” (Joralemon, 1995). Does what is offered by the state match the needs, expectations, and demands of the organ donation community?

Research Question:

The primary question linking the fields were: How are the possible configurations of self, personhood and biological citizenship reflected in and reflected upon in Canadian society, in light of the availability of organ transplant technology?

Traversing Topics:

The following topics appear throughout the fields of inquiry: a) worth, risk, safety; (b) symbolic meanings of the body and body parts; (c) accounts presented for or against organ donation; (d) gender.

Together, these form a matrix within which the medical and cultural converge at the body, the vehicle which experiences organ donation. It is this experience that the study is aimed to understand and interpret.

5.4 The evolution of the study: From pre-fieldwork to practiced methods

What originally piqued my curiosity towards organ donation and transplantation was the Government of Canada’s decision to change legislation regarding groups of people considered to be high risk donors. Men who have sex with men (MSM) were put on the list, joining intravenous drug users, people who exchange sex for money, and prisoners. MSM were

considered ‘high risk’ if they had sex with another male over the past 5 years from time of donation. To me it raised questions of worth, citizenship and identity. Who is worthy to donate? What does it say about the Government’s notion of who a worthy citizen is, and what sort of behaviours do they associate it with? In what ways could being considered ‘high risk’, based on sexual orientation, affect ones identity?

These were my original entry points, into organ donation and transplantation in Canada, the key themes I wanted to explore. What I found while doing my fieldwork however, was that the issue was not nearly as contested and controversial (outside a few circles – for example the gay community) as I had anticipated. Perhaps the issues outlined above would have been more prominent had I interviewed donor kin and members of the gay community, but time, recruitment, and resource constraints dictated that I focus on transplant recipients, the more accessible and visible members of the transplant community.

When the subject was brought up with my participants, most of whom were transplant recipients, none were aware of the recent changes. As I thought this a poor question to lead with, my interviews were more a chance for participants to share their stories, something they were eager to do. I then started to notice a pattern in recipients’ stories, themes, problems and issues common to most. The focus of my study then became wider, with some of the original objectives being abandoned so that I could pursue areas of interest that emerged from participants’ reflections, issues that I had not anticipated before hand, mainly because I was not sure who (what groups of people) I would be able to recruit.

The fields of inquiry, although they guided the creation of my interview guide, were not followed much during the analysis and interpreting of the material. Although the primary objective was quite broad, it remained relevant. The focus of the rest of the objectives, however, shifted to recipients, and their relationships to family, friends directly and to the donor and their kin indirectly, through their transplanted organ. The key themes that ended up being dealt with in this thesis are the interrelatedness and interconnectedness, or sociality of life – and death.

The new set objects to come out of the fieldwork practice are:

Primary objective:

- Understand how Canadian transplant recipients navigate and make sense of their world and their ‘new’ lives.

Secondary objectives:

- Examine what understandings Canadian transplant recipients and those around them (friends and family) have of the body and its organs and parts.
- Examine what the outcomes of their understandings are for recipients and those around them, in relation to organ transplantation.
- Examine in what way recipients deal with the outcomes of their understandings.
- Understand how recipients’ experiences with transplantation influence or are influenced by society in general and those around them in specific.
- Examine if and how recipients’ experiences differ from those presented in popular public discourses, and medical-anthropological literature.

From these objectives, the practiced research questions become:

- What are recipients’ (and those around them) understandings of the body and its organs? Are these different from other understandings present in Canadian society? How do recipients navigate their ‘new’ lives with their ‘new’ selves? And, are there any particular processes involved that facilitate or harm this navigation?

5.5 Rational for choice of methods

The appropriateness of methods can be judged by their ability to answer a study's objectives. But before we can choose which methods to use, we must be sure that the objectives can be expressed and captured in some way. The objectives of this research project have changed but as the questions being raised, issues and concepts being investigated are of a similar kind, the rational and ultimate data collection methods remain similar and are still relevant to some degree:

A phenomenon is an occurrence that is observable, perceptible to the senses or the mind and perspective can be individual and/or communal. From this definition, there must be some way to capture these perspectives. In the broadest sense, the study is trying to look at the cultural representations of organ transplantation. The question becomes in what ways are these representations evident in society and how can these be captured and interpreted

How people view themselves can be reflected in the language used to describe themselves and their mannerisms. How society views organ donation and those involved can be reflected in collective expressions such as various media discourses such as public campaigns, television and cinematic representations. Society's views also manifest in the form of public and private accounts presented for or against organ donation.

Reflections of self can be expressed through language in an interview while social identity and citizenship can be captured through visual or verbal representations the community uses. These can be acquired through interviews, observation of settings where these topics are present as public media discourses.

Whether and how people ascribe different types of symbolic meanings to various organs can be expressed individually through language, and collectively through forms of imagery in various types of media discourses. Metaphors, expressed either in written, verbal or visual form can also reflect meanings given to organs.

In order to capture these issues making up the phenomenon being investigated, the study used several qualitative methods for data collection. 14 semi-structured, open-ended interviews were conducted face-to-face with organ recipients, and living donors. These interviews were supplemented with observations in settings where issues pertaining to organ transplantation are explicitly dealt with. These settings included events held for donors or recipients, including awareness campaigns. However, other public and open arenas might be included in line with the exploratory objectives, and in order to accommodate the need to follow leads and cues which could not be anticipated beforehand. These will be elaborate upon in the 'fieldwork journey' section.

The study employed purposive sampling and subjects were selected due to their personal involvement with or knowledge of organ donation and transplantation and broader. The observations and interviews were carried out over a 4 month period.

The rationale for employing these methods is that in a heterogeneous society it is difficult to identify the specific rules that govern understandings concerning the body, self and personhood. The emergent design allows for exploring in-depth a topic on which little is known in advance. The variety of data collection methods allowed for the uncovering of deeper meanings embedded in gestures, words and opinions. I am more interested in a process, in this case how people navigate organ donation in their daily lives, rather than outcomes.

5.6 Ethical considerations

The ethical concerns that exist in the study are vulnerability, anonymity, confidentiality and informed consent (Pope & Mays, 2006). In terms of those I might interview, organ recipients

or those on waiting lists are vulnerable because of their compromised health and emotional status. To reduce this risk, only those well enough to comfortably take part in the interview will be asked to participate, and participants will be made aware that they can choose to stop the interview at anytime with no consequences. Key informants are vulnerable in the sense that any dissenting or unfavourable opinions, if not properly protected, could put the participant at risk for professional repercussions. This can be reduced through the assurance of anonymity and confidentiality of participants' responses. Anonymity and confidentiality will be ensured through the removal of all identifiers, and paraphrasing responses when necessary.

If I am not clear as to the purpose of my research, some of the participants that are considered vulnerable could develop expectations that I cannot or do not intend to fulfil. My research is non-therapeutic and exploratory in nature. This highlights the importance of informed consent, making sure the participants are fully aware of the objectives of the research as well as how the information given will be used and what participants can expect in return. This will be ensured through the use of an information and consent form outlining the purpose of the study, what will be asked of the participants, how the data will be used, measures taken to assure confidentiality and anonymity and what if any, are the benefits to them personally.

Another dilemma is the use of internet chat rooms, blogs and online postings as a source of information. Is this all public domain and therefore does not require informed consent? It may be difficult if not impossible to track down whoever made the comments in order to ask for consent. Anonymity and confidentiality can be assured by not including the website address or any online identifiers of the participants if so desired by participants.

5.7 The fieldwork landscape

Organ donation and transplantation in Ontario:

At the end of 2003 more than 1700 individuals were awaiting an organ transplant. The total number of transplants performed in 2003 was 639. The number of new patients added to the transplant waiting list grows each year while the number of donations remains stagnant. In 2001, 100 people in Ontario died while waiting for a transplant; that is one person every three days. In Canada for the same year the total was 287. 87% of Ontarians report they would be willing to accept an organ or tissue transplant but only 49% say they have signed a donor card. Ontario is a world leader in transplant, with many world's first; first heart valve transplant (1956), first successful lung transplant (1983), first successful double lung transplant (1986), and first successful liver-bowel transplant (1988) (www.giftoflife.on.ca).

Recruitment of participants:

Participants were recruited through a list of email subscribers to an organ donation and transplant blog, a mailing list for the HeartLinks online chatroom and in person at the World's Biggest Walk, and the HeartLinks' Craft and Bake Sale and Christmas Party. In an upcoming section on limitations, I will discuss the issue of self-selection bias that may have resulted from recruiting from these venues.

Description of participants:

One of the strengths of the group of participants interviewed is the wide range of backgrounds, and situations represented in a relatively small sample size. Heart, lung, kidney and liver recipients were represented as living donors. Situations ranged from a joint interview with a liver recipient and her live donor to someone of a minority background. Most participants are or have been involved in some form of volunteer work related to organ donation and transplantation, from advocacy and awareness to support. A number of participants have also been involved in other research studies, either clinical drug trials or an ongoing study looking at incorporation (how recipients come to see their transplanted organ as their own) for heart recipients, and so were familiar to research.

Interview settings:

Formal interviews were conducted at the homes' of recipients; one was at the home of a living donor, at various local coffee shops, the food court of a shopping mall, in a hospital cafeteria, and a breakfast restaurant. One interview was conducted over the phone. Four interviews were written communications conducted electronically.

Interview procedure:

Before beginning the interview participants were asked to read, pose questions about and sign the informed consent form. Where permissible the interviews were recorded, but regardless, written notes were taken. I then told participants a little bit more about the study and its objectives and topics of interest. With this information in mind, I invited participants to begin by telling their transplant story, from when they became ill, through being on the waiting list to recovery from the surgery, up until now. I had my interview guide but while they were telling their story I used it more to probe further when recipients touched upon a subject of interest. But for the most part they were allowed to speak freely, and ask me any questions. When appropriate, I would bring up various examples and undergo a type of thought experiment with participants in order to try and uncover any hidden issues, tensions or views. The thought experiments allowed us to discuss topics which if were brought up as real possibilities might have caused them distress or to shut down and lose interest in the interview. An example would be considering receiving an organ donated by a criminals. After they were done sharing their story, I would ask specific questions if certain topics from the guide were not brought up. At the end participants were invited to ask any further questions and told I could be contacted with questions or concerns at any time. I told participants that a copy of the results would be made available to them when completed. Interviews ranged from 45 minutes to 3 hours in length, but averaged an hour-and-a-half.

Supplemental material:

Although the interviews formed the bulk of the material for analysis and interpretation, other data collection methods were used to triangulate and validate the data, as well as gain a sense of the wider culture within which organ transplantation takes place. Observations and participation, which will be described in the next section, were used to focus on the language,

metaphors, and interactions among transplant recipients when discussing matters related to transplant and day-to-day life. Media analysis including newspapers, both online and printed versions were scanned daily for stories related to organ transfer (donation and/or transplant). Online news archives were also searched. Sources of popular culture including television programmes, literature and advertisements were followed as well as online discussions related to organ transfer (chat rooms, blogs, and comments to news reports).

5.8 The fieldwork journey

The process began before leaving for Ontario, Canada. Organizations involved in organ donation and transplantation were contacted to see if they would be interested in collaboration or providing resources of any kind. The range of activities these organizations were involved in were advocacy, awareness, education, support, regulatory as well as organizations for professionals in the field. While almost all were unable to provide any physical resources or collaboration opportunities, their websites provided valuable information on what subjects were discussed or not discussed and helped frame the 'expert' positions. While in Oslo I applied for ethical clearance, finalized my research protocol, interview guide and tentative methodology.

The first step upon arrival was to begin making contact with possible participants. The Organ Donation & Transplant Association of Canada (www.organdonations.ca) provided some funding and also gave contact information of transplant recipients involved in advocacy work for them. I contacted the operator of a blog on organ donation and transplant issues. I wrote an email introducing myself and my research project, attached an executive summary of my project, and asked if he would like to participate or if he could suggest ways to recruit participants. He was kind enough to forward my email to every subscriber on his mailing list. And the responses started to roll in. Interest was substantial and swift. Many transplant recipients wrote expressing interest and a desire to help. The general feeling was that

recipients wanted their stories to be shared, and were very open about their struggles with illness, transplant and recovery.

I was interested in the new trend of using internet resources such as chat rooms, blogs, online diaries and support groups as a possible source of information and avenue to recruit participants. One such example is Merv Sheppard's Transplant Network (www.mervsheppard.blogspot.com). There are a few support groups that meet in person in Ontario. One such group caters to all recipients, surviving donor kin or anyone interested in organ donation and transplantation and has three local chapters. The only problem was that they were too far away, and the bus and train schedules did not coincide with their meeting times. There is a support group for lung transplant recipients or those on the waiting list, but is based out of a hospital. I contacted those in charge but was not allowed to attend because I was not affiliated with a Canadian research institution or researcher. This was expected before hand, but I thought there was no harm in trying. For kidney recipients and those on a waiting list, there is a phone hotline staffed by kidney recipients who volunteer to act as mentors and answer questions or provide support.

I was surprised that there was not much available online that was specifically geared towards Canadian transplant recipients or surviving donor kin. Also, the internet is so vast that it can at times feel like a craps shoot of search terms. One night while 'surfing the net' the e-Gods smiled at me and I put in the right combination of search terms. I came across a support group for heart transplant recipients in Southern Ontario. They originated from hospital, and were still somewhat affiliated with them, but run independently. They not only met in person, they organized events and had an online discussion room. After contacting the administrator, I was invited to post a message introducing myself and the project and asking for potential participants. This yielded many interested responses and I soon found myself with more interested people than I thought I would have time for.

Respondents to my request were well balanced between male, female, younger and older in age and time since transplant and represented the spectrum of transplantable organs; kidneys,

lungs, heart, liver, and pancreas. I wrote a thank you email to everyone who answered my initial request, answered any questions, provided any additional information they requested and also asked them to think about possible dates and ways of conducting an interview. The bulk of the respondents were from the area of Southern Ontario, within 30mins to 2hours from here. This makes sense as I later learned that to be placed on the transplant waiting list you have to be located within a two hour drive to a transplant hospital, and three of the major transplant hospitals in Ontario were located within that radius of my location.

Based on the large number of people who expressed interest in participating in an interview, I became a little worried that I would not have time to meet with them all, or would end up with an insurmountable amount of data to analyse. But as I started to ask for some specific dates so that I could begin to make a schedule, I didn't hear back from a number of respondents. I waited a week for a response and then sent out a reminder email asking if they were still interested in participating. If I still received no response, I sent out one final email a week or two later. In almost every instance, if I didn't receive a response after the initial request to suggest dates, time and places for possible meetings, I just never heard back from them.

While I was in Ontario to do fieldwork, a number of organ donation and transplant related events took place. The first was 'The World's Biggest Walk' for organ donation. The idea originated in Australia but has now spread to many countries all over the world. The goal is to coordinate walks in the name of organ donation awareness that begin at the same time in every city participating. Unfortunately for Toronto, the closest city hosting a walk to me, the start time was 8am on a Saturday morning. And of course the weather was anything but cooperative. It was a cold and rainy morning, and I almost didn't make it because I could hardly see out the windshield through all the rain. The one plus for me was that major highways are pretty quiet at 6 am on Saturday mornings. The turnout was a respectable 50 or so participants by organizers' standards, and the spirit and attitude was the total opposite to the weather. Everyone was extremely friendly and willing to share their story with me as we walked around downtown Toronto in the rain. This event was held fairly early on in my fieldwork and provided me with a handful of participants for an interview. Also in attendance was a representative from the Trillium Gift of Life Network or TGLN (www.giftoflife.on.ca),

the organization responsible for overseeing organ procurement and donation efforts in Ontario. A visit to the organization a little later on in my fieldwork yielded a lot of useful background information and statistics on organ donation in Ontario, all of which are easily accessible online.

Towards the end of my fieldwork, the HeartLinks support group held a crafts and baking sale which I attended. There were many heart transplant recipients working as volunteers at the tables throughout the day. I was able to hold many informal interviews, which were more like 5-10 minute chats. But despite the short time we were able to talk, transplant recipients were quick to open up and share intimate details about the ups and downs of their experiences. It really helped to form an idea of what the world of transplant recipients is like, and just brought to life just how little I really knew about the ‘behind the scenes’ stuff not present in public discourses. The day did provide me with the opportunity to conduct one in-depth open ended interview with a female heart recipient. It also put me into the ‘loop’ of the support group and I was kept informed of what was going on and also invited to their annual Christmas party.

The Christmas party was more of a social event, and I was not specifically looking to ‘score’ interviews. I was more interested in observing how transplant recipients and their families interacted with each other. But it didn’t take long for one of the group’s members to take me by the hand and make the rounds, introducing me and telling them what I was up to in my fieldwork. I had the chance to speak with some very interesting characters, and gain further insight into the lives of recipients. The most powerful part of the event came when recipients and hospital staff in attendance went around the room and introduced themselves. There were not many dry eyes in the room as recipients spoke of their gratitude to their loved ones who supported them through thick and thin, the donors and their families whom they have never met, the surgeons, and the magnitude of this ‘gift of life’. What I took away from the event was a deepened sense of the fragility and beauty of life and the power of the human spirit. But that is not to say I did not also take away study material, logically speaking.

In between these events I had the privilege of meeting and having what seemed more like informal chats than data collection interviews with some amazingly resilient, tough and caring individuals. They were all extremely open, frank and quick to bring me into their inner circle and treat me like a friend, not a researcher. I even had an offer to have Christmas dinner with a recipient and her wife, whom I had just met a couple weeks earlier and had only spoken to on a few occasions. The interviews were rollercoasters as topics ranged from the serious and emotional to the ridiculous and fantastical. The meetings took place in three general settings; the homes of recipients, coffee shops or in a cafeteria at a transplant hospital. I let the recipients choose the setting, wherever they felt most comfortable and was most convenient for them.

While in Ontario, I watched the evening news nightly and checked online websites for stories related to organ donation and transplant. I also subscribed to a news service from the TGLN which compiles online stories from all over the province and provides summaries and links to the original websites. I also watched medically themed fictitious television programmes to see if organ donation and transplantation were featured. As a quick side note to the reader, the TGLN has just launched a new awareness campaign aimed at young men and women. It has been regarded by some as controversial and is worth a visit (www.recycleme.org).

Upon my return to Oslo, I began taking inventory of the materials collected, sifting through the information gathered, and listening to the recorded interviews. Interviews were not transcribed verbatim, only selected phrases or passages were written out. Interviews were however turned into narrative accounts of participants' transplant experience.

Limitations and problems encountered on the journey:

One of the limitations to my fieldwork, and one that was anticipated before hand, was the 'off-limits' of hospitals. They would have been a rich source for recruiting participants as it is a natural hub for recipients, donor kin and those on transplant waiting lists. It would also have

been beneficial to speak with transplant surgeons, social worker, and psychiatrists in order to have a representation of the medical understanding of the issues being investigated. The thesis will make much reference to the 'biomedical view' and I would like to acknowledge here that although it is presented as a single understanding, it is rarely monolithic (Lock, 2001) and it would have been good to have access to Ontario's surgeons for that reason. In-hospital fieldwork would also have given me access to the interactions around the procedure itself, and the messages conveyed to patients (donors, relatives, recipients) with regards to 'instructions for use', how to cope, etc. I chose to remain independent and not try and seek out a collaborator in a hospital setting in order to pursue what was of interest to me while staying flexible and true to my objectives.

Self-selection bias is another possible limitation. The fact that I recruited from groups of people who have become involved (i.e. low activists), for some reason, and therefore might not reflect the general transplant population. In terms of my data and material, any themes, issues and conclusions drawn from the analysis needs to be viewed from the contexts in which they arose.

A limitation related to this that surprised me was how little I could find in terms of support groups, which I had anticipated to be a major source of information, available outside the hospital setting, either physical or online that pertained to my location of study. Although I had begun the search for potential sources before beginning fieldwork, I thought that once I was 'on the ground' I would quickly be able to track down what and who I needed.

Another limitation was the inability to secure enough funding for the project. I was able to receive partial funding, but not enough to meet the budget requirements. Because of this, I was not able to travel the distance required to follow some leads. In particular it would have been beneficial to have attended some of the support group meetings taking place in other cities around Southern Ontario. But the distances were great, and I could not financially or logistically make the trips happen. A lack of funding also led to a shorter time frame for

conducting interviews. I had to suspend my fieldwork and take on a job, working full-time days for three weeks.

A limitation I had neglected to foresee was participants getting sick and suddenly having to cancel an interview. On more than one occasion, a participant came down with something, was not feeling well on that day, or felt something coming on and didn't want to chance going out in public for fear of getting worse. Recipients live out the rest of their lives in an immunosuppressed state and minor coughs and colds are quite common. In some of these instances the participants-to-be and I were unable to find a suitable date and time to reschedule.

On a couple of occasions the interview location did not permit for audio recording of the interview, and on one occasion I forgot to turn the machine on. Hand written notes were taken for every interview, but some information might have been missed or misunderstood. All attempts have been made to ensure accuracy of the information given by recipients.

5.9 Analysis

An interpretive framework of data analysis consisting of several steps will be used. Hermeneutic approach was used in analysis. My attempt to present a cultural account of organ transplantation is inspired by Crawford's (1984) use of the term 'interpretation' as "an attempt to discern meaning from what people have chosen to tell this particular researcher in the context of an interview, with all its distinct properties as a special kind of social interaction (63-64)." Interviews were written up as narrative accounts of participants' transplant stories. These narratives were read by the thesis supervisor and themes, issues, and possible interpretations were discussed until mutual understandings were reached. A focus of the analysis is on the concepts of self and personhood. My understanding and use of the terms is that they are culturally constituted, that is given and re-given meaning in a socio-cultural process of interrelatedness. Hence, as interpretive (hermeneutic) practice of linking

statements, symbols, etc. to wider contexts in order to get at possible meanings. Lock (2007) points out that “to promote donation, organs are animated with a life force that, it is argued, can be gifted, and donor families are not discouraged from understanding donation as permitting their relatives to ‘live on’ in the bodies or recipients (225).” Although I do not agree with this statement entirely (for reasons that will become clear later), it brings up some of the cultural analytical guidelines for my interpretation. The ‘life force’ she mentions, for my analysis, consists of the description of self and personhood above. I will trace its ‘life’ if you will, from donor to recipient and beyond. Self, personhood and our understanding of life in relation to health will again draw on the work of Crawford (1987) in that these days understandings are to a significant degree determined by moral generalities in the individual (e.g. to ‘choose’ right, to ‘control’ ones fate). These ‘moral generalities’ will be examined in terms of the next concept, gift exchange. The three concepts governing the act of giving, according to Mauss’ (1990) theory of gift exchange are; the obligation to give, the obligation to receive, and the obligation to repay. These concepts will help guide the interpretation of participant’s experiences related to organ transplantation, and will be elaborated upon in subsequent chapters. ‘Living on’ after death, as a concept, will also inform the analysis with regards to practices at the ending of a life, drawing on Helman’s (2007) description of burials. The concept of the ‘generalized other’ as outlined in Dodds, Lawrence & Valsiner (1997) will be used to explore the implications anonymity has on organ transplantation.

Instructions to the reader:

I will make use of ethnographic indents to present excerpts from my field notes, written or voice recorded. The use of “quotes” denotes actual words, phrases and expression of participants, unless taken from a source of literature, in which case they will be referenced. The use of ‘quotes’ denotes concepts and terms, some of which had to be created to convey the proper message to the reader. Use of the term ‘we’ refers to the reader and myself, to indicate that this is a journey to be taken together through the lives of the study participants.

6. Introduction to results an interpretation

Life post-transplant is difficult enough to deal with because of the strict regiment of medication and doctor's appointments, debilitating side effects, and changes in relationships, expectations, and life in general. On top of all that, investigation (delving deeper) into the worlds of the participants alluded me to a sense of ambiguity and contradictions in their lives. It appears they are influenced by these ambiguities and contradictions when describing the two major experiences that comprise transplant; the physical experience of being sick, and the cultural responses to the sickness and the therapy (i.e. transplantation) experienced by the recipient. The cultural responses come from society, those close to and involved with the recipient such as friends, family, and transplant staff (doctors, nurses, surgeons...). These experiences are framed by what will be described as the biomedical and the 'other' ways of understanding which might accommodate the responses from those around the recipient (meaning those in their lives). As we shall see, this cultural world is fraught with tension, and leads to some interesting and creative outlets by recipients as they try to make sense of their 'new' selves.

We will begin by looking at the experiences of a young female kidney recipient. She is 36 and single, was on dialysis for 3 years prior to her transplant and spent 8 months on the waiting list. She is about to be placed back on dialysis and the transplant waiting list because her first transplanted kidney is failing after 13 years. Her experiences of being sick and receiving a transplant nicely captures the depth and range of issues brought up many of the participants. Her reflections on what she termed the "sick role" are presented here to describe the physical experience of being sick, an event all participants had to deal with, to varying degrees, prior to transplantation. This is a written conversation she wrote and emailed to me a few days after our interview as we did not have time to discuss it. The physical and social experience of being sick will not be elaborated upon directly in subsequent chapters but is presented here because this account is representative of the backdrop to the participants' lives. As such it to some degree shapes participants' experiences with transplantation, and the cultural responses to it:

“Some premier thinker in Sociology (or Psychology) suggested that just as actors play roles on the stage, we play roles in our everyday lives. He spoke about a complex layering of these roles, such as being capable of portraying a mother, a business owner, a wife, a daughter, etc. And commented on how we move seamlessly between these roles depending on where we are, who we encounter, what we believe others expect from us is, etc. These roles are not only jobs or symbols of areas of responsibility, they are something we internalize. This internalization is what most interests me.

As a person who’s had kidney disease since 18, I’ve added the sick role to my repertoire. As easily as you would explain to someone that you’re a university student or that you’re a new mother, a person who plays the sick role will say they’re sick or mention their illness. People then reflect on their knowledge or the illness (or ask specifically about it) and then you move on in social interaction with this person knowing another aspect of you – perhaps with different expectations of you.

Because I look and feel so well I don’t usually mention I am sick. Even in romantic relationships, I mention my illness when I feel the person is ready to receive the information. It’s not that I’m embarrassed to be a, ‘sick person’ I just try not to define myself by my sickness.

When I do organ and tissue donation advocacy work, especially public speaking, I reveal my sickness like one would a card trick. No one expects me a pretty, young-looking woman to be sick; to have needed a transplant and to have a chronic illness. I know that I have made people feel differently about organ and tissue donation because I touched them by sharing my story. That is a positive use of the sick role.

The sick role is not without its trappings. It is tempting to use it as an excuse for not accomplishing things or to make people expect less of you. The sick role can be used for sympathy. The sick role can be an excuse to be in a holding pattern. Actually being sick, (side-effects from medications, disease symptoms, etc.) compounds this. Being sick can make you weary and down in a way that you feel little more than the 'sick person' at times. The fight is rising above the role, your perception of the role and other people's perception of the role.

I've been most happy at times in my life where there's been another very dominant role that trumped the sick role. Being an actor or a university student almost cancelled out the sick role completely – even though I was still a sick person. The hard times are when you're between roles, so to speak, and so because of boredom you claim the sick role because there really isn't anything else. I am not a mother or a wife either so if people ask about me, at my worst, I am liable to talk about my health, (good or bad) as my defining quality.

Work-wise, I've never been very traditional. Even now, when I write free-lance and teach E.S.L., etc., the thing that seems to define me is my poor health. As I mentioned with the dominant roles, perhaps if I were a doctor or a lawyer, the sick role wouldn't seem so dominant in my life.

Looking at this thing from another perspective, I am almost 37 and have been sick since age 18. Perhaps the sick role feels most dominant because it represents something that's been a permanent part of my life all these years. Being a student or an actor or a girlfriend were all shorter-live, transitional [transitory] roles. Being sick has been permanent. I don't remember being well anymore, being honest.'

Adding to how the sick role is reinforced, being sick touches on every aspect of your life. In my case it begins with pills in the morning, it effects what I eat, it dictates my energy level, it effects what I ultimately decide that I am capable of doing that particular day, etc. It sounds like giving into the sickness but it's simply the logistics of managing it. Why wouldn't sickness define someone, at that rate?

Ending positively, my 'sickness' has been something that I try to carefully manage and minimize. I do not want sympathy. It is not the right grounds for being the centre of attention – that is the wrong type of attention. I have fought for my sickness not to be my defining trait. Even when I did dialysis, I still had cute boyfriends and partied and travelled, even went to university. I've also fought to minimize people's perceptions of me as a sick person. I don't hide it but I don't create attention around it. If I act like it's no big deal then they act like it's not big deal too.

I can't say I'm happy that I'm sick, but I can't say I'd be as good or as smart of a person had I not been sick. I can't say I would have travelled or pushed myself to try things or took risks had I not been sick.

There is something brave, but slightly unsettling, about seeing the complexities of one's life laid out like a deck of cards in front of you.”

The many dilemmas and sentiments reflected upon above, such as coming to be identified by your illness, feelings of worth in relation to others in society, and other “trappings” of the sick role are familiar to many transplant recipients and were expressed by many of the participants as important issues they struggled with in their illnesses leading up to their transplantations. We will now look more at her experiences in relation to her kidney transplant. Her case is presented here to show the range of topics that will form the analysis in subsequent chapters.

It captures many of the dilemmas and ambivalences faced by the rest of the participants. Here is a narrative account of her transplant story, taken from field records:

For her organ transplantation is better than the alternatives of dialysis and death. Dialysis for her was like a “prison sentence”. She said it “felt like winning the lottery” when she received her kidney because “so many factors need to align” in order for the procedure to happen. Factors include the person had to sign their card, make their wishes known to their family, and blood types and other biomedical parameters had to be compatible. It was all “overwhelming” according to her.

The act of signing the card takes very little effort physically, but the fact that very few people do it makes it very profound and meaningful. Perhaps it takes a great deal of mental effort to come to the decision to donate your organs and discuss this issue with family, according to her. She was scared of the surgery, so she spent 2 ½ years on dialysis before agreeing to go on the transplant waiting list. Another reason for the hesitation was fear of the anti-rejection drugs and their side-effects. She said there is a great degree of guilt, especially if there are some days in which she is not being “productive” with her life and kidney. She has done lots of advocacy for organ donation awareness but it still never feels like it is enough to “repay” the donor. She quoted a line from Robin Thicke (a musician) to sum up her thoughts about her transplant: “why me, [but in the same line], why not me.”

She doesn't really think about where her kidney came from but her transplant was in Montreal and she said they weren't allowed to give any information. She has noticed some changes in food tastes and so believes it could have been a man in his 20s, possibly French Canadian. But she isn't sure whether she dreamt it, if it was just a hunch or if she made this up in order to be at peace with the whole idea of her transplant.

She believes that the rest of him [the donor] is buried except for the organs that were donated and the best way to honour his memory and organs is to take care of yourself. She wrote a letter to the donor's family but received no response. The letter went through an intermediary at the hospital.

She didn't follow all the rules when it came to her dialysis. She would do her dialysis at parties and in the car. She had peritoneal dialysis and so could do it on her own, she wasn't required to go to hospital. She had to have dialysis 4 times a day for 30mins each time. For her, bending the rules was a way of rebelling and having some control and freedom from the "prison sentence" that is dialysis. She was after all in her 20's when she was on dialysis.

After her transplant other people's expectations towards her have changed. She told me an example involving a new medication and how her doctor wouldn't let her change hers. At one point she felt sick and her doctor told her to just get over it and get on with life. Her doctor was against the idea of her going on disability but she had to and now feels guilty because she is not being "productive" according to society. Also her friends are overachievers and she finds it hard to keep up with their accomplishments. She would like to, but can't push herself because she would just end up getting sick.

Her expectations towards herself have also changed. The "gift" has caused her to put undue pressure on herself. She feels overwhelmed by it, and has dubbed this the "Lazarus Burden" meaning that now she is back from the dead and so she must make the most of her second chance.

Dating is difficult post-transplant for various reasons such as your health condition, and the fact that she has a dialysis tube because her kidney is failing again. She tries very hard not to see herself as “damaged goods” because she realizes how short life is. She feels she doesn’t fit in with normal society but at the same time doesn’t feel part of the “transplant community”. She feels she doesn’t fit in because of her young age, but also because of being black. Support groups are not her thing and she has never felt a part of it. A reason for this is that she wants to be outside of negative experiences and often the meetings end up being “bitch fests”. It also tends to be older people who attend and speak up at the support meetings.

At times she has been a little grossed out at the thought of having someone else’s organ inside her. She can actually see the transplanted kidney under the skin, a reminder of what she has been through. She joked about an ultrasound technician who told her to treat it like a baby in the womb and talk to it, and apologize to it for missing a dose of medication. For her, the healing of her surgery scar was a symbol of her healing mentally and emotionally.

She asked a doctor at one point why recipients cannot meet the families of their donors. The response was that donor families have this idea in mind of who is getting their organ and if it didn’t match the reality, they would get mad.

According to her, part of the problem with organ donation and transplant awareness is that this is not “sexy” enough for the media. She thought that more could be done to address differences in religion and culture as a way to improve organ donation rates. She feels we need to be more upfront about the urgency of the need for organs and a way to do this is to put more focus on people on the waiting list (when people are at their most desperate). We need to be shown how the system is failing instead of just focusing on success stories. Alternative

media forums such as facebook need to be used more to get the message out and raise awareness.

This narrative shows the complexity of life as a transplant recipient and raises many important issues worthy of discussion. In my material, an issue that I found interesting, and one that is alluded to in the above case, is an inherent tension in the lives of the participants. This tension is most often presented in the literature as a schism between the conceptualizations of the body and its parts in medicine and that of the lay person. It is also presented as “a schism between the ideals of medical science in its quest for progress and the beliefs of lay people (Lupton, 2003: 51).” Transplantation also reinforces the idea of the body as machine, a concept people borrow from technology and naturally used to conceptualize the body (Helman, 2007). In the United States, Sharp (2000) mentions “transplant professionals and organ recipients regularly reduce donors to their parts: The heart may be described as a pump, the liver and kidneys as filters (304).” This objectification and fragmentation of the body was similarly shown by Sanner (2001) who found that a main perspective among the Swedish public was of the ‘body-as-machine, in which there was an “implicit belief that the mind, personality, self and so on, were not situated in the organs...Rather these entities were located in the brain (1494).” As we shall soon turn out attention to, this dualistic thinking is one of the fundamental tenets of Canadian biomedical science.

For this analysis, this position will be referred to as the ‘just tissue’ position. Tissue here means biological material with a biological function. Although she does not explicitly discuss the topic in the accounts above, we will see later that recipients-to-be are questioned on how they view the body and its organs, and participants frequently had their organs explained as pieces of machinery by medical staff. The competing or ‘other’ understanding is hinted at; we just need to read between the lines a little. It presents itself as a tension that can be summed up as such: on the one hand, she is supposed to think of her kidney as ‘just tissue’, but on the other hand the kidney is about persons. It is harder to separate from its social origins than its physical host. If we take a look at her story, this tension appears to underlie her experiences with transplant. The tension that results from her having these two understandings, and as we shall see, is the thread that runs through the experience of transplant.

I will suggest a slightly different interpretation of this tension as presented in the literature and from it suggest a slightly different point of departure for the interpretation of participants' experiences and reflections. There exists tension because these understandings, at times incompatible and in opposition, are present in the cultural world of those involved with organ donation and transplantation. It is not a matter of either-or, there is not divider between 'medicine' and 'lay people', thus no insiders and outsiders, these understandings are accessible to all. An example of this can be found in an article by Lock (2007) in which she recounts a transplant surgeon's discomfort with the idea of receiving a heart from a murderer. Medical personnel are not immune or shut off from these 'other' understandings. This example from Lock is evidence that what we are talking about is majority understandings and conceptualizations, even though they have less – and are given less 'weight'. The "uneven meanings of bioscience in a multicultural world (Rapp as quoted in Kaufman & Morgan, 2005: 322) exert power and influence over the way people make sense of the phenomenon that is organ transplantation. Tension then results as people try to reconcile these 'uneven meanings'.

The fact that these understandings making up our frame of reference are incompatible and unequal may make people uncomfortable at times. Even though thoughts of the 'other' view might come naturally, they know that it is not the 'true truth' or 'truer truth' because of its position in the hierarchy of our conscience. Participants seem to hold both understandings, but the experiences appear not to fit the dominant one. As I will show later this gives rise to experiences and situations that are not welcome or uncomfortable for participants to discuss.

The central dilemma from which the other issues to be discussed stem is the inherent tension outlined above. The other issues that will be addressed are the incompatible understandings participants have of organs, transplanted organs specifically which is an elaboration of what has been discussed so far; the presence of a new third party in their lives coming from the fact that in some way they are now 2-persons-in-1; the 'baggage' this new life comes with, meaning the social characteristics that give it a personality and a claim to personhood; what recipients do with this 'baggage', meaning how they 'unpack' it in a sense and put it in a

proper place; and the incompatible needs recipients and donor kin have in relation to the donor and the transplanted organ. The main understandings that are at odds are the 'biomedical' or 'just tissue' position, and the 'other' position or 'organs-as-persons'. When the participant had her kidney described to her as a foetus, it became more than tissue, it was given a life of its own. It also suggests that this organ-as-person comes with rights and obligations towards caring for it. The participant entertains the possibility that the kidney (this third party) in the case above could have been from a French Canadian man in his 20s, with tastes if food different from the recipient. These social characteristics or social 'baggage' give the organ a personality. Because of this 'personified' organ, the participant feels a "Lazarus Burden" to be "productive" and "repay" the donor for the "gift". It will be suggested later on that this sense of obligation and need to do something can be looked at as an attempt to put this third party to rest. For the participant above, she is attempting to 'make peace' with her transplant by putting the memories (real or imagined in her case) of the donor to rest. We will see how this process can be at odds with donor kin's desire to have their loved ones 'live on' within the recipient.

I would like to hypothesize that these topics seem to represent building blocks, cultural or semantic components in a cultural account of 'normalization' or 'incorporation', in the turmoil surrounding organ transplantation. Normalization here is a process by which a recipient comes to feel and think about the transplanted organ as any other body part and incorporation here is a process in which the organ is accepted into the recipient's self-image (Joralemon, 1995) I am not suggesting or trying to argue that this tension or its surrounding ambivalences are something that can or need to be solved. What I will do over the next chapters is to go through the most prominent ways in which, I think, these are expressed and the conditions of their existence. This will be done by unpacking the participants' experiences and making an interpretation, giving a cultural account of organ transplantation.

7. Incompatible understandings and knowing better

As Sharp (2007) points out, despite the reductionist and mechanistic treatment of the body according to the medical establishment's understanding, which seeks to commodify the body and its parts;

“It is, in fact, quite difficult for organ recipients to think of their newly acquired parts merely as sophisticated pumps or filters... (pg.63)”

We shall now turn to the competing and incompatible interpretations of organs, and transplant organs in particular, that seems to surround my study participants. These range from describing an organ as a “unit” to a site that “measures compassion”. How else do they express how they view and think about their bodies and their ‘newly acquired parts’?

A man, who has received two kidneys on separate occasions, described his understanding of what organs are and what they mean as (excerpt taken from field record):

His view however, is that his kidney is “just an organ. It came from someone but it was not what they were like.” He wonders if any changes could come from the organ or if it is more likely to be a result of his new outlook on life. When we discussed other organs however, he thought of lungs as giving “deep breaths” and the “breath of life” but told me he “knows better intellectually.”

He admitted that an organ from a prisoner might bother him as he wonders about picking up their personality traits. But because they don't tell you about

the donor, you never know, it is all a guess. This shouldn't really be an issue if he really "knows better intellectually" that organs are "just organs."

Another participant, a man who donated two-thirds of his liver to his sister-in-law described his understanding in this way, when we were discussing the possibility of organs being more, of having personalities or retaining and carrying anything of the donor after death:

He thought that if he received a heart transplant, he might feel that somehow a part of the donor is influencing him. The "donor's soul would know where their heart is and you might feel that person's energy." It was "difficult to put into words" exactly what the participant meant, and elaborated that you might somehow be able to feel the positive energy attached to the heart. In contrast with this view (referring to a person feeling a heart's energy), he sees the liver and kidneys as machinery. Towards the end of the interview he acknowledged both the "medical" and more "humanistic" views of organs.

A female participant, whose mother passed away during lung transplant surgery said:

In terms of organ donation, she would see it as a part of the donor living on in the recipient although she views organs as pieces of machinery.

A female kidney recipient seemed to echo these sentiments when she stated that she believed she thought "the same way as others", which to her meant that people understand the heart as a "pump", but also that an organ "represents emotions (excerpt taken from field note)." People have both understandings, that organs are "just tissue", which represents the biomedical view, or that they are something more, what was earlier introduced as the 'other' or 'organs-as-persons' view. What these comments demonstrate is that commonality of these competing understandings among the study participants. She believes that everyone else

thinks this way, that an organ can have more than one interpretation, as a piece of machinery but also as a symbol for emotion. As we will see later, this is what interests me; organs have a symbolic function as a source of metonyms in that the organ comes to stand for the donor, and through this appears to live, on as expressed by the female participant above.

Asked what the heart represents to her and how she would describe it, a female heart recipient wrote (excerpt from written conversation sent out electronically):

“A heart to me represents existence; it is there to keep your body working. It is the engine that needs the fuel from the rest of the body to work. I think it represents ...life! The heart is a beautiful Organ that people believe it measures the compassion of a person... Maybe that is why a lot of people who are very caring and compassionate towards others end up in heart failure... am I biased??? Maybe!!”

The heart recipient uses the mechanistic terms ‘engine’ and ‘fuel’ to describe the function of the heart, but seems to describe a different purpose for it – as a moral compass of sorts. This ambivalence is apparent in the other comment. Organs may function as pieces of machinery, but they operate within and part of a living system – a person.

When asked how the doctors described the heart to her, the heart recipient from the above comment explained:

“The Doctors explained that this would be a choice between quality and quantity...which now when I think about it is weird because my quantity was not very long at that point... anyhow, I picked quality, thinking that even one more good year on this planet to do the things I did not get to do, would be enough for me to accept the transplant.”

The doctors described the organ in technical, scientific terms that deals in absolutes. There is no room for other possibilities or interpretation of organs in this language.

After I explained a little about the study and my interests, another female heart recipient began by telling me that (excerpt from field notes):

“Some people are freaked about having another person’s organ inside them” although she always felt she owned the heart. She attributes this to her personality and also a lack of religious belief. Despite a sense of ownership, she admits that the experience “is a bit strange.

She sees the heart as a spare part being fixed, a view she admits might seem “cold.” A major reason for this view is that after her surgery, when the doctor came to check on her he asked “How is that unit doing?” She cried for 24 hours after her transplant because she had someone else’s heart. Part of the reason was she realized someone had to have died.

This reductive description was only really solidified in her mind when the doctor referred to her heart as a ‘unit’. Reductive here means the heart was stripped of everything but its most basic descriptor; there is no mention or connotation of its function or origin. She admits to the ‘just tissue’ understanding (she sees it as a spare part), but still entertains these ‘other’ notions. Although her take on the heart might seem ‘cold’ to some, her response to receiving it was anything but. Someone who views the heart as only a unit with no social attachments probably would not cry for 24 hours. It was only after a doctor came and reassured her with a very basic stripped down descriptor of the heart as a ‘unit’ that she felt more at ease. This illustrates the central ambivalence that will be emphasized and from which many others may spring. It also illustrates the eerie feeling of knowing you have someone else’s organ inside you but knowing better. To her the heart is a “spare part”, a unit being replaced, yet the experience still is “strange” and may cause some to “freak out.”

The idea of a prisoner's heart concerns her because she would wonder what they might have done to themselves and the health of his organs. She would not want the heart of a rapist or murderer. But she also said that she would not want to drive a car that once belonged to a rapist or murderer; "It's just creepy! (excerpt from same interview as above passage)"

Here we see again that although she views and describes the heart as a "unit" and a "spare part", the thought of an organ being more, of having a life of its own as it were, entertains her. That is the possibility comes to her and is difficult to chase away, joke about or shrug off once and for all, despite the efforts of her doctor to reduce the heart to a unit. As we will see later, it is difficult to chase away because organs appear to possess a force, social in nature, which operates autonomously and presents itself to the recipient, almost ghost-like arguably.

A female heart recipient described some testing required before undergoing a transplant:

You are required to undergo psychological testing, where the participant told me she was asked about her views on organ donation. She was asked whether or not she thought she would take on the personality of someone who was of a different background or religion. She answered that she wouldn't, and told me that she looked at the heart in a scientific or more specifically mechanistic way, as a pump. She did however acknowledge that some people would give an organ a soul or a personality but that she didn't. She views the donated heart as a pump that belongs to her. But what is puzzling to her is that she now eats foods she didn't pre-transplant, but can't say whether it can be attributed to the donor's heart. If she were to think about this, she might "go mental."

Even though she knows the medical understanding to be correct, she is still aware of 'other' understandings out there, in which an organ may have a personality or soul. Despite her 'mechanistic' view of the heart, the mystery of suddenly thinking she has changes in food for

which she cannot account for comes to her, and she is puzzled by it. Again, this illustrates how the tension can lead to thoughts that are troublesome or uncomfortable to have, in that they might cause her to “go mental.”

The same participant was then asked to imagine various persons from which an organ could come from who would be termed undesirable by society.

The example we discussed was that of a murderer. She told me she hadn't previously considered the possibility that her heart could have come from a murderer. She told me of a story she either heard or read somewhere about a recipient whose donor was a murderer and how the recipient ended up eventually killing their spouse. She told me that this is an example of how we are influenced by society and more specifically media presentations, even if we view ascribe to the medical view of organs. She then asked, seemingly rhetorically: “Why would it bother someone who views the heart as a pump?”

This comment illustrates the role of media in creating and spreading around these ‘other’ understandings. The above example would bother someone exactly because whether we like it or not, these ‘other’ understandings are out there, in our faces, all the time. They have an influence in how we see things, whether we are aware of it or not. Having the “just tissue” view does not save you from these ‘other’ understandings. In the final chapter I will return to this but with an added understanding of why these representations have such salience, no matter who we are.

Together with the other recipient with whom a murderer's heart was discussed, this extreme example brings out the hidden tension, feelings of uneasiness, and dilemmas these understandings create.

Together these snippets illustrate the different understandings of the body and its parts, as well as the different meanings people attach to them. They also point to the tensions and ambivalences that arise as participants try to reconcile having these incompatible thoughts. It is easier said than done to refer to an organ as ‘just an organ’ or piece of ‘machinery’. Organs in fact come with other semantic possibilities because they come with culturally imbued meanings. We will now make an interpretation as to what these other possibilities and meanings may be, and where they come from.

7.1 An interpretation on ‘Incompatible understandings and knowing better’

A guiding premise of scientific and clinical biomedicine in Canada is that of Cartesian dualism; the fundamental understanding of the body and mind as separate. The origin of this reaches as far back as Aristotle and Hippocrates (ca. 400 B.C.) but was formulated most clearly in terms of present day understanding by Rene Descartes’ (1596-1650) dictum *Cogito, ergo sum* – I think, therefore I am. From this came the distinction between two classes of substance: the tangible body and the intangible mind. Other oppositions in Western ontology familiar to Canadian culture mirror this dualism; nature/culture, passion/reason, individual/society. It has been suggested that this is natural and useful way of categorizing and making sense of the world (Lock & Scheper-Hughes, 1998).

The result of this dualism is to get recipients to view the mind as the localization of personhood and the body as a series of parts. This view is both a necessity for and a result of organ donation and transplantation. As we shall see later, it does not solve the problems in transplantation and has some unintended consequences for the lives of the participants.

Transplant technology, the pinnacle of man’s triumph over nature is wholly dependent upon the “conceptions of the body as a collection of replaceable parts and of the self as distinct

from all but its neural locus (Joralemon, 1995)” for its success; a success that requires a steady supply of available organs, and a society willing to suspend belief (or at least push it into the background) in non-biomedical understandings of the body. But as we will see, it does not remain there for long; it comes steaming through with great momentum, a force that recipients must eventually deal with.

We must also keep in mind that organ transplants, like any phenomena, are shaped by the context in which they occur. In Canada (North America in general), it is in a society which values autonomy, productivity and health (Crawford, 1984). It is also set against this ‘spare part’ model (Helman, 1988) which is combined with a sense of materialism, ownership and property rights.

An explanation put forth by a participant is that biomedicine’s position is necessary to enable recipients to first of all agree to a dangerous surgery and secondly to minimize possible psychological distress over the fact that they are now a combination of ‘self’ and ‘other’, even if it is a benign ‘other’.

Evidence that although this might be the dominant discourse, it is not the majority cultural understanding of the body comes from the notion of psychological rejection, or adjustment stages that patients go through in which “the transplant recipient progressively normalizes the experience of a foreign organ and comes to think about it as any other body part (Joralemon, 1995).” Normalization is a relative concept, one that is as individual as each recipient, and may be more intimate than that posited by biomedicine. In a sense, when we are unpacking these issues, we are really looking at whether or not recipients do in fact normalize the experience, and if so what normalization entails and how recipients go about it. Later we will suggest that part of this process entails the need to do something with this ‘other’ presence, whatever that ‘other’ may be.

If we hold only a mechanistic view of body parts as devoid of consciousness, then why do recipients struggle with ‘incorporating’ an organ into their self-image? What then, are the other ways with which to understand and think about the body and its parts that could be causing these dilemmas? The Cartesian dualism mentioned above caused the mind (or soul as some would equate it with) to recede into the background of biomedical and dominant discourses for centuries (Lock & Scheper-Hughes, 1998). But despite all this cultural counter-work, there are still other conceptions of the body as more holistic or monistic that exists in lay people’s beliefs, even if not explicitly acknowledged or practiced. As was mentioned earlier, this is the central ambivalence underlying organ transplantation, as evident in my material.

Another way to look at or think about organs is in a more holistic or monistic way, characterized by complementary dualities in which “the relationship of parts to the whole is emphasized” where “the health of each organ depends on its relationship to all other organs. Nothing can change without changing the whole (Scheper-Hughes & Lock, 1998).” In this case, there is no way to avoid psychological, physical as well as social ramifications in organ transplantation, where ‘parts’ are being exchanged between people of differing social backgrounds.

But the body is also more than the individual, which is the “lived experience of the body-self.” We can distinguish two more levels of analysis: the social body (a natural symbol with which to think about nature, society, and culture) and the body politic (regulation, surveillance, and control of bodies – individual and collective). In the social body, the body is “good to think with” as it – and its parts and products – can be used as “cognitive maps to represent other natural, supernatural, social, and even spatial relations.” In this, it provides a rich source of metaphors, which then in turn help us to grasp intangible ideas by bringing them into our concrete realm, a frame of reference with which we can make sense of the world around us (Scheper-Hughes & Lock, 1998). The ‘other’ understanding allows for a social body, what we will turn our attention to at a later stage. What is being discussed in this thesis is the interrelatedness of people and organs through their social bodies. The individual body of the donor may be deceased, but it will soon become clear that its social body

continues to 'live on'. The body politic is being introduced here as it is relevant in producing and reproducing (or rather attempting to) the type of bodies necessary for organ donation and transplantation to be successful. We will soon see it does so by attempting to cloak the commodification (or separation of mind from body) of organs in the rhetoric of gift exchange, a process that as will become evident, is problematic to the participants.

To sum up, we have just seen the two major conflicting understandings of the body. In biomedical dualism, the mind is treated as separate from the body. Because of this, organs can be treated as 'just tissue.' But as was shown in the participants' cases, there are other ways of thinking of the body. Some of the views presented see the body as more holistic, a relationship of parts to the whole. This 'other' understanding gives ways for organs to be treated more as 'persons', in fact giving them social lives. As mentioned above, the dualistic understanding is a useful way of categorizing and making sense of the world. But as evidenced by the participant's experiences and reflections it leaves phenomena unaccounted for. The unease described in the previous chapter comes from the power of these unaccounted phenomena to refuse to go away, and by indulging in the alternative views of organs that these phenomena suggest, is tantamount to heresy, believing against 'better knowledge'. Participants may know better, but may feel worse because of it. We will now look at some of the more personal descriptions participants either gave to transplanted organs or were given to them by those around them. The recipient is now 2-persons-in-1 as it were, because of these social lives of organs.

8. The social lives of organs: 2-persons-in-1

We have just seen how living in a world with more than one understanding, allows transplanted organs to be more than sophisticated pumps or filters. They are in fact, as will be shown here, allowed social lives. This possibility also allows the recipient and those around them to view the organs in different ways. How does this affect the relationships between recipients and their family, friends, and society? How does it affect the way recipients see themselves?

Asked if she ever thought or wondered from whom or where her heart might come from, either before her transplant or now, a heart recipient answered:

“I have thought about this many times and I wrote the family through Trillium, but I never heard back from them and ever since then I have not even tried to contact them, I think I was hurt that they never responded, but I am sure they were grieving. I have wondered though many times, who the heart came from and how did they die and what kind of person they were. I had this dream, many, many times that there was a little boy with one of those big blue finger mitts for a baseball game on crossing the street and he gets hit by a car and dies and he talks to me about not feeling guilty for accepting this heart... crazy, I know, but I have had the dream several times since the transplant.”

The female heart recipient from the previous chapter, who sees the heart as a spare part being fixed, described how her friends view her heart:

Her friends picture her donor as a 39 year old male motorcycle driver who likes to drink beer. They have this description in mind because statistically this would fit the profile of an ideal candidate for organ donation. So now her friends are always asking if she likes beer, and her answer is always “no.” The recipient

believes her friends have this idea because to them the heart is not like other organs; “It is not your soul, but close to your soul.” It is a place where personal characteristics come from and are located.

Another participant, a man who has received two kidney transplants said that:

After receiving his transplant he noticed his taste in foods changing. His friends joke with him that the donor came from a certain ethnicity and culture, not only because of the food but also because of a feeling he gets when he sees a particular type of woman. He wonders where or from whom it came from, but ultimately considers it better to be left a mystery. His view however, is that it is “just an organ. It came from someone but it was not what they were like.” He wonders if any changes could come from the organ or if it is more likely to be a result of his new outlook on life.

What these cases illustrate is the practice of imagining donors. These imagined donors are a third person present in the lives and interactions of participants. The recipient is now two persons as it were. It is an environmental challenge to counter, myth to bust, that participants say impedes the processes of healing, closure, accepting and re-integrating a transplant into recipients’ lives.

A male liver recipient noticed that post transplant; the only real change has been in taste. He now describes himself as a “bigger fan of chocolate” for which he does not have an explanation.

When discussing changes in personality that might have come about post transplant, a male double lung recipient thought of an instance when he was asked what he would like from a local chain of coffee shops. He blurted out “an

iced cappuccino”, to the surprise of everyone in the room. The surprise was because when asked if he even knew what an iced cappuccino was, the recipient replied “no.” It was a craving he had but could not figure out where it came from.

Acknowledging a change for which no explanation can be given may be a way of allowing this ‘second’ person, this ‘other’ from which the organ came, to come through and present itself to the recipient and those around them.

After her transplant, a heart recipient wrote a letter to the donor’s family which is difficult because: “You don’t want to come across...you want to hit the right balance between being thankful but not gushing.” She knew what she wanted to say, but it was a matter of finding the words to say it with. One night the wording just came to her. She did not get a response back from the family. The only information she has from the hospital is that the donor was a young girl in her early 20’s. The participant wonders what kind of person the donor was and what happened to her (why she died so young). She described herself as “curious but not obsessed.”

At the time the hospital gave no information at all as to the origin of the organ. She sort of remembers hearing it was from a 30 year old male, but joked she might have been hallucinating or dreaming at the time (excerpt from field record, female kidney recipient).

A double lung transplant recipient said he tried to piece together his donor’s identity through looking at news stories, especially in the first year after his transplant.

These cases are all instances of an 'other', a 'third party' present in their lives. The participants may be 'whole' physically, but socially it seems they are anything but.

When asked if she feels different since receiving her heart transplant she explains: "I feel like a different person and I do not like this person. I am sick all the time and very negative about everything. It has been the roughest year and a half of my life and some days I regret getting this transplant."

The third person present in this case presents themselves as an altered version of the recipient, sick and negative. There is no mention of information (real or imagined) on the donor, but she still in a sense acknowledges another person present, someone different than her pre-transplant self.

8.1 An Interpretation on 'The social lives of organs: 2-persons-in-1'

Participants' friends and families will remind them that their new organs are from a '39 year old beer drinking biker man', a '30 year old male', a 'young girl in her early 20's,' someone of 'a certain ethnicity and culture', a 'fan of chocolate' regardless of how they themselves view their bodies and the transplanted organs of themselves and somebody else. The recipient is now host to these 'people'. The couple of instances in which this 'other' person was discussed by joking may be an attempt to hide the tension that results over thinking of oneself as hosting another person's organ.

The reason a recipient can be 2-persons-in-1 is because the two understandings allow for two very different interpretations which are:

“The body as mere thing carried by a triumphant science and technology, and the still present sense that the body and its parts are always more than things...that the ‘person’ is inextricably tied to the sheer materiality of the body or its parts (Rabinow as quoted in Joralemon, 1995).”

But the descriptions offered by the participants speak of more than the materiality of their donors. They are hints at the ‘social materiality’ of the body or its parts. The donor is still tied to their former identities, be they real or imagined, because organs, like persons, have social lives. Although organs are also given social meaning by virtue of being transplanted, that is not the primary sense I got from the responses of the participants (Sharp, 2007). What is being suggested here is that these organs retain their original social meaning, inherent in the social life of its materiality. They carry with them social identities belonging to original their ‘host’, that is original ‘location’. And this appears to be autonomous, it happens regardless of what you believe in. That is why, later, I will be considering analogies to zombies and ghosts.

And as we have seen in the previous section, there is no room for such possibilities in the biomedical understanding of the body and its parts. This was evident in participants’ interactions with transplant staff in which organs were described as ‘units’, ‘pumps’, and ‘filters’, descriptors they all ascribed to. Participants also described a process of psychological testing before undergoing a transplant that serves to pathologize the ‘other’ view. These are attempts to separate organs from their origins and isolate them to mechanistic functions. From the ‘other’ point of view, this is tantamount to ‘de-animating’ and ‘reducing’ the body into a series of replaceable ‘spare-parts.’

But as we have just witnessed, these attempts are unsuccessful. The donor, this ‘other’ person still comes through and presents itself to the recipient and those around them. Sharp has suggested that this is part of a process of reanimating the dead (organ). This entails a reanimation of memories, reconstructions of the donor self and the reassignment of original identities (Sharp, 2007). In light of the material presented in this thesis, the term reanimation does not aptly describe what is happening. The term places the phenomenon too squarely on the recipient, which might misrepresent the experience we are witnessing, that is an

automatic, logical phenomenon that happens despite efforts to suppress or know better. Also Sharp is speaking specifically of instances where recipients and donor kin break from and subvert transplant's doctrine of anonymity, meet each other and form new bonds of kinship. None of the participants (except in the case of the two live liver donors) have met any surviving kin. In the case of live donation, the recipients and donors knew each other prior to transplantation.

I am suggesting another interpretation. Judging from participants in this study, there is no need to re-animate, re-construct, or re-assign because they are never truly de-anything. Rather it is as if the organ is already animated at transplantation and is still so afterwards. It is animated according to the original meaning 'filled with life'. Here, it is filled with social life. This points to a more autonomous agency on the part of the organ. It also suggests that there is something feeding this animated organ, that is, something is keeping it animated. The force behind this animated organ I suggest comes from our everyday understanding of the social nature of life and how it lives on after death in the memories of those other people who have been party to that life. Hence it is 'socio-animated'; filled with social life through our interconnectedness. Every individual lives on in the minds of others. It pushes through biological death because as a social force, it has a momentum, much like a tidal wave continues to roll on after it starts or a tanker-ship continues to cut through the water after its engine has been shut off. This social force is not stopped by the biological death of the donor because as just mentioned it is present in the memories of others.

The instances in the material that indicate a haunting character, are one in which 'the thought of who' (the donor is, was) comes to everybody, regardless of the belief in a "metaphorical view"/holistic or mystic belief in the capacity of organs to actually carry over personality traits; and despite "knowing better". As an example, recall the heart recipient above who has had a recurring nightmare about her donor being a little boy who was hit by a car. What I would like to suggest is that 'the thought of who' (personality) is propelled by the recognition that the organ was originally in 'somebody' (personhood). The personhood (social, embedded in interpersonal relations) of the organ is *inevitable*, the (belief in the) personality is *optional*.

The term 'vital' is often used to refer to the 'vital' organs, those crucial for existence, which make up the 'gift of life'. It is not hard then to imagine a double entendre in that these organs are not only 'vital' meaning essential to biological and physical existence, they can also be seen as essential to one's social existence. This social 'vitality' of organs stems from the fact we need social interaction in order to thrive in life; it is part of what defines us as 'human'. For as the expressions go; "No man is an island" and "Man is by nature a social animal."

To sum up so far, according to this interpretation of the participants' reflections, what is required is neither a reanimation, nor a de-animation like the attempts of biomedicine. Instead it appears that some participants deal with this momentum by 'domesticating' it; taking a natural occurring phenomenon and channelling it, putting it to productive use. By doing so it appears they are able to attenuate this momentum, finding an outlet for this social force that accompanies the organ after transplant. The fact that this 'other' person appears to present themselves regardless lends itself to the possibility that, or suggests that there is a force behind it, one that participants may have trouble domesticating, and that is why it appears to 'haunt' them. They have trouble taking control of and domesticating this force because others have a say in its existence, fuelling it in a way.

Like a tanker ship or tidal wave, there is a lot of weight to this social material. And like these heavy entities, it is hard to stop them abruptly. This social material starts with a name and builds throughout the vast experiences that make up a life. Although now the recipient may be viewed as 2-persons-in-1, we only know the one person. In Canada we are rarely (allowed) to know who the 'other' person was, so we fantasize, imagine a generalized donor, drawing on stereotypes. For example in one of the cases presented in this chapter, a participant wondered why the donor died so young. There is this notion of 'candidacy', dealing here with early death and donor status susceptibility. We will return to these concepts of a 'generalized other' and 'candidacy' in the next chapter.

We will also see later on how this social force affects the lives of recipients, and what they do with it. This is after all a reason why we have burials, to put to rest the social nature of a

person, a logical consequence of having had a life. I mean to add nothing mystical or religious to this. It is grounded in our everyday understanding of life, what makes a person, and what happens after death.

Recipients, like the rest of us, inhabit this world in which both these understandings are present - and presented to us in many ways. But despite biomedicine and transplant's best efforts to convey the dead nature of the donor, the statements made by the participants suggest things are not so black and white. The organ appears to come with identity claims, in other words already animated with a social force that travels through, presents itself and appears to move with its own momentum. But this social force is not the only thing to come with the organ. The 'other' person doesn't come alone; they are much more than an age and a gender. We will now see how these part(s) – literal and figurative – come with what one participant described as 'baggage'.

9. The social baggage of organs

Below is an excerpt from field notes taken in an interview with a male liver recipient, married with kids. His priorities changed completely after his surgery due to the dramatic effect the experience had on him. Before he used to be driven by a need to succeed in business, but now puts family first no matter what. In fact he now stays at home with his kids. In his case someone had to die for him to have a transplant, which was traumatic for him to think about;

“You want to know what happened, what kind of family they left.” Some of the first thoughts he had after his surgery were “what happened to this person, who were they...How can I best take care of this organ and carry on their legacy?”...

He wrote a letter to the family of his donor and received a response. In the letter he learned that the donor left behind children and he once in a while finds himself wondering what they are up to, how they are doing. This was especially true in the first few years after transplant. Although you never forget and the donor and their family is always in the back of your mind, by the third or fourth year he started to define the “new” him. Other things he learned about the donor were that he enjoyed watching sports, loved pasta and candy, especially chocolate. The recipient admitted to me that in light of this information, he finds himself “gravitating” towards candy, M&Ms in particular (small, candy coated chocolate buttons similar to Non-Stop)...

Before his transplant he never thought about or pictured the person from whom his liver might come from. He started to picture the donor a little bit afterwards, especially when he got the letter from the donor’s family. He found himself “trying to read between the lines” of what was written.

For a female heart recipient, her story is a little different, and she was somewhat hesitant to share a detail with me regarding her donor:

In a very rare move, the transplant doctors came in to talk to her about the donor's history. During his life, he suffered a fall and had an aneurysm and also had cancer when he was a kid, although at the time of his death he was cancer free. The doctors explained to her that they felt it was a healthy heart, "and that was all" the recipient needed to know. Their professional judgment and opinion was good enough for her...

After her recovery she wrote a letter to the donor's family which was for her a "cathartic exercise." When she got a response she was "stunned." "It was the most beautiful thing." In the letter she learned a lot about the donor. What I found interesting is the way it was written. Instead of making reference to the donor, the family writes;

"You have received a heart that was so generous. That heart won a humanitarian award in high school."

Organs appear to come transplanted with meanings from their original contexts, the donors' lives. They come with identity claims; which gives organs symbolic attachments. These identity claims in the examples above are of the original donor, but in the previous section we saw how organs can also be infused with an identity of a more generalized kind.

A female heart recipient responded about her views of the body and its organs in terms of any symbolic or metaphoric meanings attached to them:

"I do not have any new things that I do or am interested in and I believe that these things come from within and not from a donor's organ. I think some people are so excited that they are able to do new things that they take advantage of it and because it is different then what they may have done in the past, they say it is because of the donor. Maybe I am wrong, but I give credit to

those who have had a smooth process and are able to enjoy a happy and healthy life with their new organs. I actually think I am jealous of these people...

I do not believe in the histories of donors being carried on. I do not think that is possible. Maybe I am closed minded, but I just do not see how it could possibly happen. Maybe people change after their surgery and, like me, become a different person, being that in a good or bad way, they believe the change was due to their new organs donor... and who know, maybe they are right, and if not, then maybe, like religion, it is nice for them to have that comfort to turn to and admire...

I believed that people are destined to have what they are given from the time they are born... I felt bad though, I must say, because I am small, I felt like I may have got the heart over a child who was waiting and that really bothered me and still does to this day. So, I am aware that not all transplants can go perfectly, I guess I was just hoping I would be in that percentage that made a difference and was able to go out and show the world how wonderful it is, but in fact it has done the exact opposite for me. I have been sick consistently, exhausted most of the time and have had many, many issues. I am depressed and angry and sad and frustrated yet I still have that hope inside of me that things will turn around.”

Her experience is counter to the dominant portrayal by media and transplant organizations, which could be seen as a source of tension. Even if you believe that organs are mere pieces of tissue, you can still worry about who is getting them or not getting them. She does not appear to give the organ ‘baggage’ from the donor, but it still comes with ‘baggage’ of sorts; it is not without its feelings of guilt that it could have gone to a child.

Asked about any groups of people she might feel uncomfortable receiving an organ from or donating an organ to she responded (from same conversation as passage above):

“The only people I would object to having their Organ(s) would be people who are terminally ill, people who are infected with any disease (Hep B, Aids etc). Other than that I am not prejudiced in any way. People are people and everyone has a purpose I believe. Of course, no one wants their organ from a paedophile or something, but I think we have to put a little faith in who the organ is coming from and because we will never know, just not think about it too much, and never try to get information on this person... you may not like what you hear, but it would not change who you are, until you hear it.”

Here we see that if you don't have information, you can believe what you want, or try to ignore the situation all together. But this is easier said than done. Even if you try not to think about it, it appears inescapable because of this 'baggage', real or fictitious, that allows organs to be more than 'just tissue'.

A male liver recipient who met his wife after his transplant discussed some of the issues of dating:

Some of his concerns were with the stigma attached to liver diseases (cirrhosis and hepatitis-C) coming from irresponsible or immoral behaviour (alcoholism, intravenous drug use or unprotected sex). Also when dating, people might come to identify you by your transplant. He does not see it as his defining characteristic, merely a part of who he is, a brief chapter in his life. Of course this would lead one to question when to tell their partner about their transplant.

For his wife, who was also present for the interview, concerns that arise at some point are questions like:

“Will I have to take care of this person later in life? Will they get sick because of their transplant?”

When the liver came up as part of a larger discussion on organs and possible meanings associated with them, a male kidney recipient raises questions of worth for the recipient:

“Why are they getting it? What happened to the first one? Do they deserve it?”

These instances of ‘baggage’ are a stereotype related to unsavoury and illicit behaviour that liver diseases conjure up in people’s minds. The fact that this comment comes from a fellow transplant recipient demonstrates the power and reach of stereotypes. We will see in the interpretation how these questions of worth bring the ‘generalized other’ to light.

Another heart recipient, who we met earlier and had the heart described to her as a unit said that according to her:

Changes in her personality and priorities have nothing to do with the heart directly. A friend of hers however, could not believe that someone could remain the same with another person’s organ inside. She never really thought about the heart and how she viewed it until diagnosed with heart disease. But now, she would describe the heart as a “spare part that doesn’t bring anything with it” when transplanted from one person to another. To her this presentation should be an industry standard within medicine (which it is) because;

“If you are into the metaphorical view, there could be a lot of baggage that comes with it, as opposed to going to Canadian Tire and buying a new set of tires.”...

For her it also depends upon your upbringing: “If you were brought up to believe your soul is in your heart and the others around you believe it, then it might be difficult to separate the two.”

This case illustrates that even sceptics or non-believers such as herself have a hard time of stripping the social bags off the organ. This suggests that whether an organ comes with this sort of baggage or not seems not to be a question of belief. However, if one ‘indulges in it’ seems to be a question of individual preference or belief.

9.1 An interpretation on 'The social baggage of organs'

The memories, cravings, and information about the donors' lives from the reflections above I suggest, are all parts of the organs' 'personhood'. These examples of personhood are the donor's social 'baggage'. It is this baggage that gives organs their identity claims. The organs come with identity claims because they are remembered by someone as having a life, along with all the social connections that entails. The origin of this is in our everyday understanding of life, that is, our familiarity with what a life is. What everyday life is taken to mean is; in general it is infused with others, in a way that binds people together by means of common experience and memories, afflictions, obligations and dues, and the myriad other ways in which humans are interconnected. In terms of understandings of health, these days they are to a significant degree determined by moral generalities in the individual (e.g. to 'choose' right, to 'control' ones fate) (Crawford, 1987). The way this social baggage presents itself is through an organ's ability to function as a metonym, in which it comes to stand for, or represent, the donor and their life. I am not describing a mystical or religious phenomenon but rather a social one, in which its content "is given through our experiences as living beings as well as our observations of living beings (Gordon, 1998)."

It is in these questions of worthiness raised in the cases above that the generalized other shows its face. In the absence of specific information to the contrary (i.e. the specific other), the 'other' (donor) is taken to have generalized rights to gratitude, commemoration and compensation (through the recipient's guilt, community work, advocacy, etc. these 'do-goodism'). So what the liver transplant case is about, is whether the recipient 'matches' the moral standards of his donor. So what appears to be going on is a kind of post-transplant moral matching of donor and recipient, informed by the symbolic meanings of that particular organ (the liver in this example), in the particular cultural anatomy of lifestyle choice ; health-ism. The same matching might go on with other organs vis-à-vis candidacy. Another participant, a liver recipient, mentioned how "the liver gets a lot of bad press" because of the association to hepatitis-C and alcoholism. But what must be kept in mind is that it is not just the liver getting

the bad press, it is also the 'owner' of that liver. The donor is remembered by someone, including the recipient. Because in many of the participants' situations, they were given no information and cannot meet with the surviving kin, the identity being claimed is that of a 'generalized other' of society's norms and normative presentations.

As was just mentioned, organs have metonymic functions. Here metonym meaning one entity is used to refer to another based on some type of connection, grounded in our experience. In this case the connection is that of a part to the whole (Geest & Whyte, 1989). Because of this metonymic function organs 'survive' the change of ownership after transplant. But; "This is not to deny that the passing from one owner to another may change the "life" of a commodity and may place it in a new context of meaning. But basically it retains its value, independently of who owns it (Geest & Whyte; 350)." As things, organs "are transacted from one interpretive setting to another, retaining value but changing meaning (pg?)." It will be shown in the next chapter that according to participant, their transplanted organs retain value as "precious" "gifts of life" but as we have seen from the material thus far, their meaning can be quite different.

In this way "human organs are never just neutral objects or 'things'. As parts of living people they carry with them a great deal of symbolism. Organs such as the heart or brain are also interwoven into everyday language, as powerful metaphors. The heart, for example, is not just a muscular pump; it is also a universal symbol for love, emotion, personality, courage and will. For many people, it is the essence of '*personhood*' – someone can be described as 'good hearted', 'hard hearted' or '*broken hearted*'. Thus, heart transplants, even today, can have a powerful symbolism for those who receive them, since it is a process where someone 'sick at heart' 'takes a heart' from a donor, so that they can now be as '*hearty*' as before (Helman, 2007: 42-43)."

Popular speech is peppered with familiar images of health and illness. This is a commonly observed trait in Euroamerican society (Crawford, 1984). In my material we see it in the mention of "units", "filters", and "pumps" as well as in the awareness website mentioned in

the methodology chapter. The body is also seen as a machine, the heart (“ticker”) as the engine which may break down. The terms “spare part” and “battery” as well as a plumber’s model with associated pumps, pipes and filters are familiar in describing health problems (Helman, 2007). But metaphors of the body and its parts extend to our everyday vernacular as well. The heart is probably the best known, with expression like “heart to heart”, “sweetheart”, “heart of gold”, “change of heart” and even “black heart”. They tend to be descriptions of personal characteristics, what many might equate with manners of the soul. This is equal to a type of ‘cultural anatomy’, in which the body can be ‘dissected’ into a series of cultural symbols, with their associated metaphorical and metonymical meanings.

It is apparent from the reflections of the participants that what organs mean are a range of things related to the ‘personhood’ of the donor or of any life-in-particular. How organs mean is through their ability to capture and then present these characteristics of ‘personhood’ to the recipient and those around. Their meaning can be understood in terms of the experience and conception of life.

To keep with the baggage and force analogies, we can think of these instances related to the donor as pieces of clothing or knick-knacks that give weight to the bag or suitcase. The more weight an object has the more force it is able to generate. This force is then hard to stop, it carries on under its own momentum. All we need to do now is add the word ‘social’ to the analogy. We are describing the social knick-knacks that give weight to the donor’s social baggage. One participant above summed it up nicely by saying it is their “legacy” they left behind. But we have just pointed out that this legacy is not passive, it is an active force in the lives of recipients as continues to move on past death (that is, to be present after death), independent of the donor, fuelled the social momentum that is a life.

The explanation we are looking for then is not how people energize the organ or the process, but how to de-energize or what was suggested earlier, domesticate this force as part of a process that accompanies incorporation and normalization. Let us now turn to how participants seem to deal with this identity claim. The ‘baggage’ described above comes

rights, responsibilities and obligations expressed by recipients towards their transplanted organs, the donors and their surviving kin. We will now see evidence of this as expressed by recipients as feeling the need to do ‘something’ with their ‘new’ organs, their lives, and the social force behind them.

To sum up, this section demonstrates a cultural anatomy with moral validations and secondly the ‘imposition’ of these meanings – that they are hard to evade and thirdly, they result, in my opinion, in a range of different responses, including the topic of the next section –a need to do something. Or rather, the need to do something arises from the social life-beyond-death that is facilitated by the transplant, and qualified by the symbolism of different organs, linking the recipient to the donor through the organs as metonyms.

10. The need to do something

Organ transplantation forces us to face our mortality, our fears and anxieties over life and death, the realization of how short and fragile it can be and most importantly in this case, the dependence on others as a prerequisite of survival. It is similar to descriptions offered by survivors of disasters and near death experiences. Surviving what in most recipients' case is a fatal condition can change their perspectives. They all attested to the life altering power of transplant and how they try to not 'take things for granted.' As a female heart recipient describes:

One of the biggest steps in recovery is accepting your transplant, to learn from it and to use it to help put things in perspective. For her, everyday is an adventure because "this is all bonus time." She also believes that "there has to be a reason why things happen" and for her, it was so that she could use her story to inspire people and help them to understand that life can be fragile and short. This philosophy (that life is fragile and short) has lead her to become a mentor to heart transplant patients (pre- and post-transplant) and is one of the reasons "why I am still here." Volunteering is also a way of making the most of a second chance by making a positive difference. She likened it to a stone causing ripples after it hits the water; "I want to be the stone."

The recipients in my study expressed the need to do something with their 'new' lives, which I will suggest is an attempt to attenuate this social force we have been examining, by putting it to productive use. They feel a responsibility for and an obligation to the organ, the donor, their surviving kin and society exactly because it is not just an organ or 'just tissue'; it is so much more, for the reasons outlined in the previous chapter, namely that they have social lives, and thus identity claims. As one participant, the ex-workaholic liver recipient said:

“Every once in a while I feel the need to do something related to organ donation.”

A live liver donor described how he viewed his transplant relationship to the recipient, his sister-in-law:

She (his sister-in-law) became more aware that she has a responsibility to his liver because it was a gift. There were no strings attached to his donation, “It’s not mine; it’s yours, so you do what you want.” But he confessed that at the same time he wouldn’t want to see his liver abused or mistreated the same as any gift you give to another person.

After her heart transplant, a participant had many complications and has ongoing problems. She feels that physically she has good and bad days, but mentally she feels worse. She has:

“Not felt like myself and it is very hard to explain this to people cause you hear the same thing over and over “you should be grateful for this gift and that you are alive”. I am truly grateful for the gift, but do not feel like I am alive, only merely existing at this point.”

This comment shows the distress caused by her experience being at odds with the ‘dominant’ understanding portrayed in the media and organ donation and transplant organizations that life post-transplant is undoubtedly better by nature of the gift, superior quality of the organ, and a second chance at life.

Another female heart recipient made a similar comment that:

She feels a bit guilty that she is not “giving back” like other transplant patients but she feels she has more important responsibilities, like raising her teenagers and staying healthy.

She may not be “giving back” in terms of volunteer work, but she is making the most of her ‘second chance’ and not letting it go to waste, by focusing on her children. It needs mentioning here that this particular guilt may arise from my selection bias, considering many participants were recruited from advocacy environments. But it does not take away from the point that transplant intensifies the felt obligation to do something with your (second, gift-enabled) life.

One participant, a female heart recipient began her transplant story by telling me that:

“You don’t forget the dates” of events related to your transplant because you “have been given a second chance.” With this second chance comes a feeling of obligation to make the most of it, as the participant put it “Don’t blow it.” For her this entails volunteering as a mentor in a special group for stage 4 heart failure. She is also participating in study, a clinical drug trial because “if it helps humanity, why not?”

Like the kidney recipient from the introduction section, there is pressure to not ‘blow it’. Some participants put this pressure on themselves, but it can also come from our common understanding of just how precious this ‘gift of life’ is. In media and daily interactions with society, they are constantly reminded just how lucky they are. It is easy to see how recipients could feel like it is more than an obligation, it is a ‘burden’ as was described in the introduction to the interpretations. Although some participant put pressure on themselves to do something good, the point is that this obligation arises no matter what. It arises from the haunting presence of the giver in the gift. It is the strings of the gift, for there is no such thing as a free gift (Mauss, 1990).

In the back of her mind is an ever present thought of being thankful. She does her best to take care of the organ as a way of honouring the sacrifice they (the donor) made.

Doing 'something' can take many forms and could be as simple as taking care of their body and the new organ it houses. She is not just taking care of it for her sake; she is doing so out of a feeling of obligation towards the donor. But these feelings aren't always 'repaid' to the donor, their organ or their surviving kin, as a male recipient of two kidney transplant describes:

His experience with organ donation and transplant has made him more grateful of life, especially the first time which was "a real high" for him. Afterwards, he and some friends started an education and support group for kidney patients. He was also an advocate for the cause of organ donation. Part of the reasons was that he had lots of free time which he didn't know what to do with because he wasn't tied to the dialysis machine. Another reason (for starting a support group) was that he was appreciative and understanding of what other patients awaiting kidney transplants are going through.

For every gift there is an (expectation of a) return gift. In fact, one support for the haunting-thesis is to be found in Mauss' account of how some dimensions of the giver is embedded in the gift, which affects the recipients, as an obligation to return the gift (1990).

This sense of responsibility and obligation can extend beyond the donor, their organ and surviving kin. For example, a male liver recipient described that for him:

There was also a sense of obligation to give back to the country in terms of financial contributions, in light of the public health care system. Regardless of the opportunities that might present themselves as a result of transplant, big decisions always need to be made, and we questioned just how life changing a transplant is and how greatly it affects those decisions. In short, transplant recipients don't take things for granted anymore.

A male double lung recipient described how inviting me into his home to spread the word about transplant is important for him because:

“How else do you pay it back and say thanks for your life?” He likes to help out the cause of organ donation but “everything in moderation”. He still wants to be himself and to keep an identity other than transplant (a common way of referring to recipients). For him, volunteering is also a way to thank society. One of the best ways in which to do this “is to take care of your organ” because these are “valuable organs. You don't squander them. You are getting something very precious and very rare.” Besides doing volunteer work, he and his wife try not to take things for granted because he knows his “projected life expectancy is lower than average now.” For them, this entails doing more travelling together.

There is a balance to be found between gratitude and moving on with your life. The fact that he still wants to keep a life separate from that of ‘transplant’ suggests that in some way he is trying to find closure, putting his transplant to rest. This is a topic we will explore in detail in the next chapter. For now we will look at possible reasons for the participants' feelings of responsibility and obligation.

10.1 An interpretation on 'The need to do something

Recipients have been given a 'second chance' because of a 'gift of life' and expressed a need to repay that in some way. I will make an interpretation in attempting to dig beneath the surface to uncover some of the hidden meanings motives, and insights. We can begin by asking "why"? Why this need or feeling of obligation? Participants make specific reference to repaying the donor and their organ. Why the need to give meaning and purpose to their transplant? Why the need to do volunteer work? One interpretation given (Helman, 2007) is that donors may help those less fortunate than them because they cannot repay the donor personally. We will return to this point shortly, but first let us revisit a statement from above and look at why: "Every once in a while I feel the need to do something related to organ donation."

As we have seen, there is cultural resistance to the materialist and mechanistic – two further legacies of Cartesian dualism - conceptions present in the medical community's discourse. People have understanding and experiences that don't match, and this causes difficulties. Something is needed to bridge this gap and minimize this disconnect. For this reason, an attempt is made to link transplant surgeries with "social values that are sufficiently powerful to minimize the sense of a disjuncture between traditional concepts of personhood and those consistent with transplantation (Joralemon, 1995: 335)." The social value (that is hopefully powerful enough) promoted by the organ donation and transplant industry/community is that of altruism, embedded in the cultural logics of gift exchange.

In the province of Ontario, organ donation is presented as the "gift of life" in medical, promotional, and popular accounts of transplant such as a newswire service offered by TGLN in which stories featuring organ donation, transplantation or a related topic are collated and emailed to subscribers. Also information from the various agencies present in the province doing awareness, advocacy, and support mimic this rhetoric. The way organ donation and transplantation is represented in and presented by all parties involved follows what is presented in the literature (Sharp, 2001).

The gift rhetoric, which posits organ donation and transplantation as the ultimate act of altruism, runs into problems because the sorts of acts proponents seek to connect organ donation to are;

“Caring responses to personal tragedies even when the individuals affected are strangers and there is no expectation of repayment. The generosity of strangers, the heroism of the person who risks life and limb to rescue those he or she does not know, the coming together of neighbourhoods in mutual support at moments of natural destruction (Joralemon, 1995: 344).”

These same heroic acts and the generous, altruistic characteristics driving them are the same ones that give organs their ‘vitality’ and are the same ones that can form ‘fictive’ bonds of kinship, of which continued contact and interaction would be a natural outcome. Here in lies the difference: these may be acts organ donation seeks to embody, but in the instance described above, the parties involved would be able to meet, reunite, and socialize due to an intense bond formed from going through such an ordeal. The affected are strangers but seldom remain so afterwards. An example is that on 9/11 all air traffic over North America was grounded, and planes already in the air were diverted to various airports. Many small towns in Eastern Canada and the Maritime provinces played host to these commercial flights, many filled with American passengers. The local people opened up their homes, offering a place to sleep, shower and eat while stranded strangers waited for the airspace to open up again. Since then, many passengers have returned for ‘reunions’.

This is where the ‘generalized other’ argument comes full circle. In the absence of identified donors (visualized or imagined instead as a generalized worthy other or giver), and in the presence of a public health care system as the prerequisite facilitator and practitioner of the procedure itself, the logical recipient of the return gift is the generalized other in its manifestations as ‘community’, ‘society’ and its higher purpose, that is over and above the interest of any one individual citizen.

The reasons that the organ-as-gift ideology is at odds with the dominant cultural model are that “one of the most characteristically human activities is the treatment of the dead as though

some quality of the ‘person’ is still present. Equally panhuman is the assumption that the self and the body are integral to one another (Joralemon, 1995: 347).” What is not stated in this however, is what that still present ‘quality’ is. This quality, as we have already suggested, is the complex web of social interactions and relationships experienced over a life time and represented metonymically by the transplanted organ. It is the social baggage of the giver described in a previous chapter, embedded in the gift and which “appropriates the non-materialist conception of the body that underpins traditional views: that is, organs remain meaningfully connected to self via the act of generous sacrifice (Joralemo, 1995: 347-348).” The quality of the ‘giver-in-the-gift’ adds to the sense of incorporating an entire person when being host to a transplanted organ. The terminology chosen here ‘host’ versus ‘recipient’ is a bit ominous. The sense alluded to here is perhaps more appropriately described by the term host; you become host to the social baggage of the organ that you receive, of which you are recipient.

Calling it the “gift of life” has implications and connotes certain images, images familiar to our popular consciousness or understanding. As a correlate, it is related to the idea of organs coming with ‘incorporated obligations’. In movies, television sitcoms and cartoons I have seen throughout my life, a plot that came up was a notion a “life debt”, meaning that you are forever in debt to someone who saves your life. It is usually presented in a comical way, but what happens is that the one who was saved becomes an indentured servant to whoever saved them. I would like to hypothesize that one can imagine recipients feeling ‘in debt’ to the donor (and organ) in some way for having their ‘life’ saved by this ‘gift’. It perhaps goes to show how media and popular understandings (lay or common knowledge) work behind the scenes to shape how we think about, view, and react to certain topics or phenomena.

The transplant industry may be trying to champion the gift as a “transaction completely devoid of social relationship (Ohnuki-Tierney as quoted in Joralemon, 1995: 343)” by coupling it with a reductionist view of organs as mere tissues or pieces of machinery but our participant’s reflections point to the opposite, that efforts to de-socialize the relationship between donor and recipient are not successful in that they are not able to empty the organ of such potential meanings. We have seen that these ‘gifts’ retain a connection to the donor

through their social baggage, and presents itself to us through metaphors and metonyms. The organs in fact come with rights and obligations, a social force felt by the recipients after the donor is dead, buried and put to rest. What the need to do something indicates, from the material presented above, then, is not so much a need to empty the organ, but to put its personhood to rest, through what was describe earlier was equivalent to domesticating the organ's social force. In the next section we shall look at how this need for a "proper burial" may be at odds with the surviving kin's desire to have a memory live on.

11. Recipients, donor kin and incompatible needs

Although organ donation and transplantation considers anonymity as a prerequisite for success, participants described instances where donor families and recipients are able to interact. You may know who is a recipient and who is a member of a donor family, the gatherings still adhere to the code of anonymity. One such place is the Transplant Games, a version of which is held in Canada as well as internationally:

Where donor families give out medals to the recipients at the events. In the opinion of a male double lung recipient, it is therapeutic for the donor families to mix with recipients; it is part of their grieving process. Some families are able to “simply rejoice in the fact that they had an opportunity for a loved one to give life.” Other families become introverts and spend all their time doing promotion and making others aware that their kin was a donor. It becomes an all consuming cause to them.

Are these instances where donor kin and recipients can interact a way for both parties to meet their needs? Can donor kin see their loved ones ‘living on’ in the recipients, their organs allowing participants to run, jump and play sports? In what way would this help recipients put the donor to rest? Is it through being able to interact and ‘thank’ donor kin and donors (indirectly), not necessarily their donor’s kin but a type of ‘generalized other’?

One of the participant’s wife works for the organization in charge of organ donation in the province (TGLN) in Family Relations, which deals with donor families:

We discussed support services available for donor families. There are donor recognition ceremonies in which medals are handed out to the families of donors. They were once open to recipients, but now only donor families are able to attend. When I asked why they decided to separate the two sides, an explanation given was in case there were any possible objections to the recipients or donors’ lifestyles that might come to light while interacting.

What this excerpt illustrates is the moral quality of personhood in health, given the emphasis on lifestyle choice as a determinant of health, and ultimately, indicator of moral worth (Crawford, 1984). In the interview she also mentioned her experience with donor family and how some think of donation and transplantation as a way for their loved ones to live on in some way.

A female kidney recipient discussed how she rarely thinks about her transplant and kidney these days, but after some probing said that actually she thinks about it a lot. She described the transplant as “part of my life” and that maybe she thinks about it so much because other people remind her, for example people bringing up her transplant birthday or having to go to a doctor’s appointment: “Even though you don’t think about it much, people remind you.”

Below are some more obstacles participants seem to face while attempting to put the social force, the organs personhood, to rest.

Some questions that ran through the mind of a male kidney recipient while writing and after sending the thank you letter to the donor’s family were if their expectations towards him would be met or would they be resentful that he had life and their loved one doesn’t? Would the family think that maybe he stole their [the donor] life? In order for him to accept that his transplant was ok, he first had to resign himself to the fact that he had nothing to do with the donor dying. This sentiment of accepting but not blaming yourself for the donor’s death is shared by other transplant recipients.

The family also wrote that they forwarded the recipient’s thank you letter to their friends and family urging them to raise a glass in a toast to the recipient.

She has since written again but has yet to hear back. She told me that at first after her transplant she thought about the donor's family everyday and still thinks about them, although not as often.

It took her 9 months to write the thank you letter. She would sit down every single day and try to write it. After she wrote it she felt like "a weight lifted off of me." She felt guilty it took her so long to write the letter and put a lot of pressure on herself to do it because the way she was raised was that you "always thank someone for a gift." It was a real turning point for her when she finished it.

Maybe in the sense of bring a type of closure, helping the recipient to put it to rest and move on with her life.

When discussing his donation, he said he got a lot out of it mentally: "A good feeling to know you helped somebody. To do something you will be remembered for."

This quote is from a live liver donor, and points to the understanding that somehow, a part of us lives on in the memories of others. He went on to think of what might happen when recipients and donor families met:

He thought that if you identify with the donor, it might make incorporation easier. But he acknowledged the flipside where if you found out information about the donor you felt was undesirable, you might not accept it. Not knowing much about the recipient can be hard on the donor family also as they might have question like "Where is the organ now? What is it doing...is it being taken

cared of?” He sees organ donation as being a last good deed, not so much trying to live on in someone else.

11.1 An interpretation on ‘Recipients, donor kin and incompatible needs’

“In most human societies people have, in effect, *two* types of death: one biological and the other social... While biological death is the end of the human organism, social death is the end of a person’s social identity. This takes place at a series of ceremonies, including the funeral, where the society bids farewell to one of its members and reasserts its continuity without him or her... During the period between biological and final social death, the deceased’s soul is often considered to be in a state of limbo, still a partial member of society and potentially dangerous to other people as it roams free and unburied. In this transitional phase the soul still has some residual social rights, especially over its bereaved relatives (Helman, 2007: p.231).”

The reasons we have burials is that it appears people’s social biographies may outlive their physical bodies because memories of a person can live on in the minds of others. Recipients are aware of this but because, as claimed earlier, recipients don’t know the identity of the donor; they remember them through an identity of a generalized kind or maybe remember a ‘generalized other’ which represents the donor. The argument here is that unless we deal with this social longevity of this ‘generalized other’ we run into problems, problems that may at times be linked to some kind of danger such as instances of hauntings or living-dead.

Examples of this can be found in other cultures, for examples sailors lost at sea off the coasts of Madagascar who return to land to haunt the inhabitants (Sharp, 2007).

What then are the implications for transplantation where some see the donor’s identity as ‘living on’ in the recipient after being ‘incorporated’? Is the donor’s soul (or in our case their social life-force) in a perpetual state of limbo, and potentially dangerous until it is ‘buried’ in some way? Is this potential danger what transplant doctors and support staff would label as ‘pathological behaviour’, an example of which is recipients identifying in some way with

their organ and through it, the donor? Are these reasons why recipients seem to find ways of de-energizing, that is ‘domesticating’ this organ and process?

Perhaps we can look at the concept of memories as a replacement for the soul in this technological, medicalized society surrounding transplantation. According to Hacking (1995), in *Rewriting the Soul*, we have learned to replace the soul with knowledge, and science. According to him, memory becomes the new terrain for spiritual battles. Although the soul that has been ‘scientized’ was something metaphysical, Hacking uses it “to invoke character, reflective choice, self-understanding, values that include honesty to others and oneself, and several types of freedom and responsibility. Love, passion, envy, tedium, regret, and quiet contentment are the stuff of the soul (215).” It is this secularized understanding of the soul (and its modern equivalent – memory), that is our social life-force which organs stand metonymically for. It can be summed up as follows: A person (in our case an organ which stands metonymically for a person) “is constituted not by a biography but by a remembered biography...A human life becomes conceived of as a story...A soul is a pilgrimage through life (218).” This pilgrimage does not end, socially speaking, with biological death. It continues on through the memories of the living and in the case of transplant, I suggest, through the vital, social force embodied by the organ.

Due to the anonymous nature of organ donation and transplantation, recipients are in a way excluded from practice of funerals and burials surrounding not only the donor’s physical death, but also their social death. These are after all not so much for the deceased as for the surviving kin, other family, and friends (Helman, 2007). The recipient is then left to find a way of putting this ‘person(hood)’ to rest. There are sanctioned ceremonies but Sharp (2007) presents evidence suggest that they are not sufficient or appropriate in relation to donor kin and recipient needs for mourning, and commemoration. In her cases, donor kin and recipients often express sentiments ranging from disappointment to outright anger and disgust with these events.

“In most traditional societies the dead do not really die – at least not in a social (or emotional) sense.” They remain ‘omnipresent’, invisible members of society or as Kaufman & Morgan (2005) put it ‘the dead make the living.’ “In Europe and North America, the care of cemeteries and gravestones, the planting of memorial gardens, and the erection of memorials, are all ways of not only memorializing the dead, but also keeping in some continuing contact with them. (Helman, 2007: p.233)”

Lock (2002), speaks of the “twice dead” donor; dying once with the declaration of brain death, and dying again once life sustaining measures are ended and the organs are removed. But could we say that the donor dies 3 or 4 times? There is also a social death, the end of a person’s social identity, but what about the ‘death’ of this force, the donor’s memory? This ‘death’ might be more of a sensitization or accommodation, a symbolic burial. Does it happen, does the donor ever really ‘disappear’ or ‘die’ socially? There may be too many reminders of what transplant recipients have been through, and the origin of ‘their’ organ. Examples from my material are transplant “birthdays”, doctor’s appointments, strict anti-rejection medication regimes, as well as physical scars from transplant surgery.

As Joralemon has noted, rejection, a very physiological, medically understood process in some way strengthens the recipient’s consciousness that their transplant identity is a compound of ‘self’ and ‘other’ because the body never accommodates the presence of foreign tissue. Recall from previous chapters that what is being described in this study is more than just “foreign tissue”; it is the foreign social baggage of the ‘other’ and its reminders. Rejection as presented here has a double entendre. It can refer to either the rejection of what may be their preconceived notions and cultural beliefs (those that do not conform to Western biomedicine) or to the rejection of biomedical attempts to reduce, mechanize and de-socialize organ donation and transplantation while finding a solution that makes sense to their world view. Joralemon argues that what is needed is an equivalent to a cultural immunosuppressant, “designed to inhibit cultural rejection of transplantation and its view of the body (1995: 343).” In the interpretation of my study material, there seems to be a need for a socio-psychological equivalent of the immunosuppressant, anti-rejection therapy; one that will allow for

integration/incorporation into the recipients personality without conflicting between organ (alien) and host person (indigenous).

Perhaps our bodies cannot accommodate this social force and so an appropriate ‘anti-rejection’ therapy is needed. This ‘therapy’, I would like to suggest, that the instances and examples of ‘doing something’ with their new lives that participants gave in the previous section may amount to the socio-psychological immunosuppressant. These ‘do-good-isms’ and other means of remembering, memorializing, commemorating are ways of allowing for the integration and incorporation of the organ without conflicting with the host because they create an acceptable outlet, a space for the sociality of the ‘other’ to exist, by not ‘deleting’ them in the sense of totally assimilating the organ into their subjectivity.

The normal course of events and natural progression of any life-in-particular is that social death follows a physical (biological) death. But transplant messes this up. It punctuates this (cuts holes in it literally and figuratively) order and we have been trying to describe what comes out (oozes out) of the holes. Social death is in a way postponed because a part of the donor is not only physically living on, but also socially living on in the memories of the their surviving kin, the recipient, and those around them. Transplant, it can be argued, disrupts the conventional order and what we are describing is what rises from the ashes.

From this interpretation, I would like to suggest, albeit tentatively, that the needs of donor kin and recipients may not be compatible. First because identification raises the potential for objections over morality, lifestyle and worthiness, and secondly, because donor kin may have a desire to let live, which recipients have a need to put to rest, and incorporate the organ as their own, which could seem to require the organ’s de-identification with the donor. To sum up then, what needs to be kept in mind is that people can’t or don’t just disappear, because they exist in the memories of other people. This is a general fact, a logical consequence of the relational and social nature of life. In order to reflect on the experiential and social dimensions of transplantation, I will now attempt to think the phenomenon I have described through the

prisms afforded by some circulatory representations of non-conventional or inappropriate social death.

12. Zombies, phantom pains and ghost: De-technifying transplantation

The anonymous nature of donation and transplantation described above leaves recipients (and to an extent donor kin – whose loved one's body is not 'whole') with no 'body' to mourn, which has parallels to ships or airplanes lost at sea. Surviving kin of these disasters often struggle with having no physical ground upon which to mourn and memorialize their loved ones, on top of having no tangible body to bury. This is also similar to the unidentified soldiers and those left behind at war zones, often far from home (Sharp, 2007).

The social force that I have been describing can be likened to a 'reversed phantom pain'. With phantom pain, the person feels the missing limb or even organ in some cases, whereas here, the organ carries the continued presence of the missing person (donor), which is felt, as it were. We feel their presence (social force) meaning we 'remember' them, through their act of donation. We don't remember them personally in that recipients don't have specific memories of the donor, but rather a representation of them, the 'generalized other' of organ donors and donation. Moreover, we are aware that they are remembered whoever they were.

A treatment for phantom pains involves desensitization and one can wonder if what is required is a 'social desensitization' which would mitigate the harmful effects of the organ and reduce or eliminate recipient's negative reaction to it. In the language of popularized psychology, it is about "finding closure". In terms of my analysis it may be more appropriate however to say that what is required is being sensitive – perceiving and reacting appropriately - towards this 'reversed social phantom pain'. Sensitization is a process of learning in which the subject is repeatedly exposed a stimulus in to progressive amplification of a response follows repeated administrations of a stimulus. Being sensitive to it could involve making a disciplined and acceptable outlet or space for this force.

Zombies and ghost as circulating representations of inappropriate death arise when people are not given a proper burial either physically or socially, meaning that their “material”, physical or social is not put to rest, upsetting the conventional order of bereavement. Also, as was previously mentioned, this social force of organs seems to carry on under its own momentum, which points to a more autonomous nature on the part of the organ, arguably ghost-like or zombie-like.

When we use the term zombie or ghost, we are referring to a way of labelling or dealing with an untimely and inappropriate death. It is this notion of putting something to rest properly (burial), and when we are unable to do so, the imagery evoked is that the souls become haunting and dangerous. Certain forces that are at play, be they discourses or practices, can either work for or against the creation of ‘zombies’ and ‘ghosts’. My understanding of ghosts, based on my upbringing in the cultural and historical setting relevant to my study, is that they haunt those who didn’t treat them well while alive or they haunt because they died a tragic and horrible, often sudden death; or sometimes they were a horrible person in life, now condemned to roam the earth after death, unable to cross over into the other side. This description is similar to those depicted in popular cultural accounts such as movies, television and the internet. For an example of a common understanding, enter the terms ‘ghost’ or ‘zombie’ into the popular, free, open encyclopaedia - . Wikipedia (www.wikipedia.org).

Modern representations of zombies depict them as the product of science gone awry (the classic example is George A. Romero’s ‘Night of the Living Dead’, or for a more futuristic take, check out the ‘Resident Evil’ trilogy, based on a video game). They are social commentaries on our fears and anxieties, highlighting the unease towards biomedical and scientific research coupled with technological innovations marching us into an uncertain future at seemingly breakneck speed. The subject of ghosts and zombies was not discussed with participants, but some of the questions and images related to organ transplantation this raised for me were; What about the image of zombies feasting on the flesh of the living for sustenance? Can this be compared to the notion of cannibalism? Can we imagine zombie organs (either the result of an improper burial or medical science) needing to feast on the flesh of the recipient in order to survive? Can we look at the organ as being brought back from the

dead? How about the recipient or the donor for that matter? With traditional zombies, the one brought back from the dead (or dead-like trance) is thought to be under the control of a necromancer. Is the recipient then under the control of the organ? Or is it the organ under the control of the recipient? Perhaps both are under the control of the anti-rejection medications, without which they would not survive.

Recipients and donor kin might not want to entertain such images (e.g. zombies, ghost, and cannibalism) and may even consider such comparisons offensive, but they serve a purpose as outlets for our anxieties and as social commentary for popular cultural understandings. They are a way to take the pulse of public opinion/understanding, gauge people's comfort level, because such notions and presentations (e.g. those in the media) are an indirect way to discuss taboo and difficult subject matter. What these images primarily indicate is the general anxiety linked to inappropriate death, and the significance and importance attached to the proper management of death and burial. From their circulation, they indicate the quality of the cultural imagination surrounding the issues raised by organ transplant, namely as capable of creating intense and existential discomfort, identity distress, and danger.

Some might say the images and interpretations provided in the previous chapters may sensationalize transplantation, and to that I apologize. The intention is the opposite; it is to give justice to experiences that are a bit shameful to articulate within the dominant 'just tissue' understanding: the feeling of being haunted, of feeling new tastes, fantasizing about the donor, etc. Rather than pathologizing such experiences and phenomena, the very existence of the zombie and ghost images should serve to reassure us and the participants in particular, that there is no wonder such phenomena appear, especially if you grow up to such stories.

I would like to sidestep briefly, before summing up, to the original objectives; the notions of citizenship, identity and worth were not dealt with in detail and ended up not being the explicit focus of the analysis, meaning they were not the themes of any chapters. They were however useful guides, key terms that framed the initial reading of the material. Even so, it is apparent my material that these concepts are ever present in the background of participants'

lives, they pop-up and present themselves at various times and in various forms. They come through with a force to be reckoned with, whether participants ascribe to these possibilities or not. They come through in relationships with those around them because as has been pointed out, people can have more than one understanding of the body and its organs. This can lead to many conceptualizations of what organ transplantation is, what it entails, and what it means for the individual and society.

I bring up these issues in an attempt to de-naturalize and ‘de-technify’ transplantation, and point out its social character, and shed light on the ramifications thereof. I do so by linking partly to phenomena that are considered exotic (ghost, and zombies) and partly to ‘hyperscientific’ or ‘pseudoscientific’ phenomena (cell memory), which will be addressed in the concluding remarks. What I hope to accomplish is to flesh out the experiential ambiguities, and to do so in a way that counters the reductive effects of biomedical discourse. This is important because I hope to add to the insight that can be drawn upon in educating patients, donors, donor kin, recipients, and counter the biomedical perspective’s dominance in that arena.

13. Concluding remarks: Cellular memory as a bridge between understandings

“Cellular memory is the speculative notion that human body cells contain clues to our personalities, tastes, and histories, independently of either genetic codes or brain cells (<http://www.skeptdic.com/cellular.html>).” It can play on our fear of losing our personality and control over our consciousness, our most intimate and human of qualities. The fact that we would lose control over these to a stranger whom we know little to nothing about is even more unsettling. The same can be said of zombies of old, the products of voodoo, raised from the dead and now under the control of a necromancer. One can imagine the transplant recipient, whose is under strict pharmacological and medical ‘control’ in order to be kept ‘alive’ in there newly ‘resurrected’ state. Or maybe we should say it is the organ that is under this control, suggesting it is a zombie, and the recipient is merely the host. The relationship of host to ‘other’ and the notions of control and rejection also parallel the idea of possession. We can imagine the recipient being ‘possessed’ by the organ and in need of ‘exorcising’ these cultural ‘demons’ (the memories and characteristics – the social life-force – of the donor).

But I would like to end with a more positive image and present cellular memory here briefly, as an attempt to bridge the mysterious to the scientific. The term only briefly surfaced a couple of times during my fieldwork but participants often hinted at or leaned towards ‘scientific’ explanations to describe their experiences with transplantation. But as has been shown throughout the preceding chapters is that organ transplantation is just as much a cultural and social phenomenon, as it is a technical and medical one. It has some parallels to the social force discussed in this thesis in that it is a way for the donor to live on, to be present and ‘felt’, through cravings, or changes in food tastes or personality. I suggest from this, that the idea of cell memory may in a sense rehabilitate the experiences of the participants, and give them legitimacy and credibility within the biomedical regime of what’s true and adequate, and what’s myth, fantasy and inappropriate or pathological.

14. Appendix 1: Inventory of materials

1. One email interview: A female liver recipient.
2. One phone interview: A female kidney recipient.
3. Twelve in-person, formal interviews: Hand-written notes taken for all interviews, with 9 voice recorded. The breakdown is 2 interviews with living donors, one female and one male, both donated a part of their livers, 1 woman whose mother passed away during transplant surgery, 1 male lung transplant recipient (wife was also present during interview and contributed on the role of the support person), 4 female heart transplant recipients, 2 male and 1 female liver transplant recipients (the female recipient was interviewed with her female live donor), 1 female and 1 male kidney transplant recipients.
4. 3 months of email news service from the Trillium Gift of Life Network. This service provides summaries and links to news stories in Canada where organ donation/transplant or related topics are featured.
5. An information package from the Trillium Gift of Life Network including FAQs, background information and statistics for organ donation/transplant in Ontario, Canada.
6. Information from the CTA (Canadian Transplant Association), including CDs with photos from the Canadian Transplant Games and an informational video shown to schools.
7. Television portrayals of organ donation/transplant during a three month period. Organ donation/transplant was featured on 'Grey's Anatomy' and 'ER'.
8. Personal journal documenting the fieldwork experience.
9. Events attended where organ recipients and people in the field gathered and where organ donation/transplant was the focus: The World's Biggest Walk for organ donation, the Heartlink's annual craft and bake sale, and the Heartlink's annual Christmas party. During these events, informal conversations with approximately 12 people were conducted. Notes were written up after the events.
10. Hand-written notes where written up as narratives, outlining the participants' experiences with organ donation/transplant.
11. A website from the London Health Sciences Centre (Canada) Multi-Organ Transplant Program which features an interactive Recipient Quilt
http://www.lhsc.on.ca/Ways_to_Give/MOTP/Share_Your_Story/Recipient_Quilt.htm

and Donor Quilt

http://www.lhsc.on.ca/Ways_to_Give/MOTP/Share_Your_Story/Donor_Quilt.htm.

You can click on a patch of the quilt and read a story about that person. There is also a Recipient Gallery

http://www.lhsc.on.ca/Ways_to_Give/MOTP/Share_Your_Story/Recipient_Gallery.htm where you can click on a name to read a more detailed story about the person.

12. One of the live donors sent a copy of his proposal entitled: “Cross Canada Motorcycle Ride To Raise Awareness For Organ & Tissue Donation” as well as copies of his blog entries throughout the ride.
13. A draft copy of a “Support Person’s Survival Guide” create by a group of people caring for transplant recipients throughout the process. It was born out of frustration over the lack of preparatory, practical and logistical information provided to family/friends that are taking care of loved ones.
14. Short email questionnaires submitted by 4 participants, 1 from a participant who was interviewed in person.
15. Program and Panel Abstracts from the conference “Intersections of Life and Death: Artistic and Philosophical Representations of Organ Donation and Transplantation” put on by the Health Care, Technology and Place organization, the Trillium Gift of Life Network and the Munk Centre for International Studies at the University of Toronto.
16. Newsletters provided in PDF format from HeartLinks, transplant patients of the Toronto General Hospital.

15. Appendix 2: Interview guide

Demographics:

Age:

Sex:

Civil Status:

Religion:

Organ(s) received and time since transplant(s):

Time spent on waiting list:

Self & Self Identity

Q: What are your views towards organ donation and transplantation?

Q: What were your concerns, fears, worries or questions:

When you were told you would need a transplant?

While you were on the waiting list?

While you were recovering?

After you were feeling better?

Q: Do you feel different since receiving your new organ(s)? If yes, how so or in what way?

Q: What do you see when you look in the mirror? Do you see any changes from before you received your transplant?

Q: What are your views or beliefs about life and death?

Q: What are your views about the body and organs? Is there any symbolic meaning to them?

What does the heart represent to you? How would you describe the heart? How did the doctors describe the organ (to be replaced) to you? Was it different to your understanding of

the organ? Has receiving an organ transplant changed your views on the body in any way? As an example, do you believe that organs have histories (from you or the donor) outside the body that carry on after death and transplantation?

Q: Do you think about your transplant and new organ on a daily basis, sometimes, or rarely in daily life?

Q: What do you think others see when they look at you?

Q: Have you ever felt guilty or not worthy of receiving your transplant? Why or why not?

Q: What medications are you on and what are your views/how do you feel about taking them?

Personhood & Social Identity

Q: Have your relationships with those around you changed since receiving your transplant(s)? If yes, how so or in what way?

Q: Have your expectations towards others changed since receiving your transplant(s)? For example, your expectations towards family (spouse, children, relatives), friends, employer, co-workers, or society in general? In what way(s)?

Q: Have the expectations towards you changed since receiving your transplant(s)? For example, the expectations of your family (spouse, children, relatives), friends, employer, co-workers, or society in general? In what way(s)?

Q: Were you given any information as to the background of your donor? Did you ever think/wonder about from who or where your organ might come from before you got your transplant? Did you ever think/wonder about it after your transplant?

Q: Have you had contact or met with your donor or donor family members? If not, would you like to? Why or why not? Do you think he/she/they would be interested? Why or why not?

Q: Would you be interested in learning the identity of your donor?

Q: Are there any groups or type of people you would feel uncomfortable or not accept an organ from? As an example, consider the some of Health Canada's "high risk" groups: prisoners, men who have sex with men, sex workers, non-medical intravenous drug users. Explain why or why not? Conversely, are there any groups you would feel uncomfortable

donating an organ to (if your organs cannot be donate, pretend they could)? Explain why or why not?

Q: How do you feel organ donation has been portrayed in the media?

Q: Do you follow/subscribe to any media sources related to organ donation/transplantation (e.g. information websites, blogs, support groups, chat rooms...)?

Medical or Biological Citizenship

Q: Tell me about your experiences being an organ recipient.

Q: Tell me about your experiences with medical staff.

Q: Tell me about your experiences with support groups and other recipients

Q: Where there any issues that you were not prepared for during your experience from illness to post-transplant?

Q: Are there any support services in your community, outside of hospital?

Q: Is organ donation a visible issue in the media and your community?

Q: Where there any public awareness campaigns in recent history that you can remember?

Q: Where, if any, should blame rest for the lack of available organs?

Q: What do you think can be done to improve organ donation and transplantation?

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