

**DIRECTED AND NON-DIRECTED LIVING ORGAN
DONOR NARRATIVES**

**“DON’T REJECT ME:” DIRECTED AND NON-DIRECTED LIVING
ORGAN DONOR NARRATIVES AND THE CONSTRUCTION OF
THE ORGAN DONATION AND TRANSPLANTATION PROCESS AS
A MEANINGFUL EXPERIENCE.**

By

MARTINA BOYCHUK, B.A.

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AUTHOR: **Martina Boychuk, B.A. (York University)**

SUPERVISOR: **Professor Ellen Badone.**

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Abstract

The organ donation and transplantation process is a highly emotional experience for directed and non-directed living organ donors. However, both types of living organ donors construct the process as a meaningful experience because, through the act of offering a kidney for donation, they help to extend the lives of those diagnosed with end-stage renal failure.

I argue that directed and non-directed living organ donors are active participants in the organ donation and transplantation process while they are patients of the Ottawa Hospital Renal Transplant Clinic. Moreover, through negotiation and, at times, social manipulation, directed living organ donors and their family members, include or exclude others as potential donor candidates.

The Ottawa Hospital Renal Transplant Clinic refers to the organ donation and transplantation process as giving the “gift of life.” However, my research on directed living organ donor narratives suggest that donors construct the kidney as a reciprocal gift, analogous to gifts given at Christmas or anniversaries. Furthermore, the directed living organ donor narratives suggests that through naming, gendering and imbuing the kidney with personality traits reflective of the donor, the kidney is understood to be an extension of the donor’s self.

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Chapter I

“Don’t Reject Me:” Directed and Non-Directed Living Organ Donor Narratives and the Construction of the Organ Donation and Transplantation Process as a Meaningful Experience.

Introduction:

Organ donation and transplantation is frequently used to extend the lives of those diagnosed with end-stage renal failure (Hogle 1999; Lock 2002). In Canada, more than half of all kidney transplants occur between related living organ donors (directed donors) and anonymous living organ donors (non-directed donors) (Trillium Gift of Life Network Act 2006). Given the high percentage of living organ donation, my research explores the narratives surrounding living organ donation as a subjective, and lived experience. These narratives derive from organ donors themselves, a transplant nephrologist and a living donor coordinator, and therefore aid in determining how the organ donation and transplantation process is constructed as meaningful. Specifically, I focus on what these narratives say about the pre-transplantation process within the Ottawa Hospital Renal Transplant Clinic and the post-transplantation recovery process within the Ottawa Hospital. In addition, I focus on what donor narratives reveal about determining who will donate, and about how to overcome a recipient’s refusal to accept the offer of a kidney. Finally, I examine how the dominant clinical narrative refers to the kidney as an altruistic, “gift of life,” while the donor narrative constructs the kidney as a reciprocal gift, analogous to gifts given at Christmas and anniversaries, which is named, gendered and imbued with the donor’s personality.

Theoretical Framework:

Throughout this thesis, I use Merleau-Ponty's (1962) *Phenomenology of Perception* to discuss directed and non-directed living organ donors' subjective experiences of the organ donation and transplantation process. Specifically, Merleau-Ponty (1962) argues that there is no Cartesian separation between mind and body. Therefore, a person experiences the world completely and holistically through their body (Merleau-Ponty 1962). As a result these subjective experiences are often recounted through first person narrative (Carel 2008). Following Merleau-Ponty's perspective, directed and non-directed living organ donors experience the organ donation and transplantation process through their bodies, which they offer up for diagnostic testing and the surgical removal of a kidney. In turn, directed and non-directed living organ donors recount their experiences of the organ donation and transplantation process through first person narrative, which constructs organ donation and transplantation as meaningful.

Building upon Merleau-Ponty's (1962) interpretation of phenomenology and Havi Carel's (2008) emphasis on using first person narrative to describe a person's subjective experience. I expand upon Deborah Lupton's (1995) argument that, through education, a patient becomes an active participant in the medical encounter. Developing this argument, I discuss how directed and non-directed living organ donors actively engage with the organ donation and transplantation process. Additionally, I use Scheper-Hughes' and Lock's (1987) concept of the body politic and Foucault's (1977, 1989) notion of the docile body to discuss how directed and non-directed living organ donors change from

being active participants in the medical encounter, to becoming passive participants during the post-transplantation recovery process. Finally, I use Marcel Mauss's (1967) interpretation of gifting and his argument that a gift is reciprocal and reflects the substance, or spirit of the person giving the gift, to understand how directed and non-directed living organ donors and the Ottawa Hospital Renal Transplant Clinic interpret the gift of a kidney.

Methodology:

After completing an expedited ethics review and receiving ethics approval from both the Ottawa Hospital Research Ethics Board and The McMaster Research Ethics Board, I began my ethnographic fieldwork at the Ottawa Hospital Renal Transplant Clinic in June 2009. The purpose of my fieldwork was to examine how directed and non-directed living organ donors construct their experience of the organ donation and transplantation process in a meaningful way through narrative. My research was informed by previous work on illness narratives, which has focused on the narratives of individuals suffering from pain or chronic illness (DelVecchio-Good et al. 1992; Good 1994; Kleinman 1988, 2006; Mattingly and Garro 2000; Mattingly 1998). In a Canadian context, Arlene Macdonald (2006, 2009) has already conducted research on transplantation from the perspective of the recipient and to some extent from that of living related donors. However, my research focuses exclusively on the organ donation and transplantation process from the perspective of living donors, both directed and non-directed, those who are unrelated to their recipients. Moreover, I examine how living

organ donors reconcile the medical rhetoric surrounding the organ donation process, which constructs it as a “gift of life,” with the actual experience of donating an organ.

A total of nineteen living organ donor participants, one transplant nephrologist and one living donor coordinator were interviewed for this project. Of the nineteen living organ donor participants that were interviewed, two of the donors were non-directed living organ donors. These non-directed donors had never met their recipients. Finally, I also briefly interviewed five family members who were directly related to the living organ donor participants.

According to Lesley Sharp (2006) the public and private narratives of organ transplant recipients follow a chronologically ordered, prescribed format. This format is also apparent in the narratives of the donors I interviewed, which may be related to the fact that donors are not encouraged by the Ottawa Hospital Renal Transplant Clinic to publically share their narratives. I relied upon semi-structured, open research questions in order to encourage directed and non-directed living organ donors to discuss their experience with the organ donation and transplantation process. Moreover, I was able to conduct interviews with living organ donor participants who were at various stages of the organ donation and transplantation process. For instance, three living organ donor participants had donated six months to a year prior to participating in the study. One living organ donor participant had yet to donate when she participated in the study, but has since successfully donated. Fourteen living organ donor participants donated between three and four years prior to participating in the study and one living organ donor had donated 50 years prior to participating in the study. The purpose of including living organ

donor participants at various stages of the organ donation and transplantation process was to gain a better understanding of the motivating factors behind the willingness to donate an organ and of possible changes in a donor's interpretation of their experience over time.

I interviewed seven male living organ donor participants and twelve female living organ donor participants. Their ages ranged from late twenties to mid-sixties. Moazam's (2006) anthropological study on living organ donation in Pakistan focused on how gender plays a decisive role in organ donation and transplantation, with more women donating than men. Similarly, the sociological study by Simmons et al. (1977) on living organ donation noted that women were more likely than men to donate a kidney to a loved one. However, in my study there were approximately equal numbers of male and female living organ donors and it seemed that socioeconomic status played a more significant role than gender in determining who donated a kidney.

A transplant nephrologist and a living organ donor coordinator were interviewed in order to gain a better understanding of their role within the clinic setting. Open-ended interview questions were used in order to ascertain participant's thoughts and feelings surrounding the organ donation and transplantation process. I asked living organ donor participants between seven to eleven open-ended research questions regarding when they donated, whom they donated to, and why they had chosen to donate. I also asked them to describe the best part of the organ donation and transplantation process and the worst part of the process. Similarly, I asked the transplant nephrologist and the living organ donor coordinator seven open-ended research questions regarding their roles as members of the transplant team at the Ottawa Hospital Renal Transplant Clinic.

Interviews were conducted at the Ottawa Hospital Renal Transplant Clinic, which is located on the fifth floor of the Riverside Campus of the Ottawa Hospital. In 1999, the Ottawa Hospital Renal Transplant Clinic became one of the busiest transplant programs in the country after performing 54 kidney transplants in a year (Organ and Tissue Donation Program 2009, A). Dr. Anderson, a transplant nephrologist at the Ottawa Hospital Renal Transplant Clinic, confirmed that in 2009 the Clinic performed a total of 71 kidney transplants: 31 from deceased donors and 40 from living donors. The Clinics status as a major kidney transplant centre made it a privileged location for research. Furthermore, the Ottawa Hospital Renal Transplant Clinic was chosen as a research setting because I had been a patient of the Clinic when I donated a kidney in December 2006.

Interviews with participants were between 45 minutes to an hour in length and were conducted around the living organ donors' scheduled visits to the transplant clinic. Living organ donor participants were recruited using a recruitment letter distributed by employees of the Ottawa Hospital Renal Transplant Clinic. During the interview process, every effort was made to explain to donors that refusal to participate in the study would not adversely impact their care or treatment at the Ottawa Hospital Renal Transplant Clinic. Moreover, all participants were given time to thoroughly read through the informed consent form and to ask any study-related questions before signing the consent form. I took field notes during the interview and I also recorded each interview, which I later transcribed and sent to each participant. Participants were asked to read over their individual interview transcripts and to decide whether or not to edit their responses. Only

two living organ donor participants edited their responses asking that I omit certain parts of their interviews. All informed consent forms are kept in a locked office at the Ottawa Hospital Renal Transplant Clinic.

In accordance with the Ottawa Hospital Research Ethics Board, all data pertaining to this study will be kept for 15 years following the termination of the study. At the end of the retention period all paper records will be disposed of in confidential waste or shredded, and all electronic records will be deleted. Furthermore, each living organ donor participant was assigned an independent study number and pseudonym in order to protect their confidentiality and anonymity as stipulated by the Ottawa Hospital Research Ethics Board. However, many living organ donor participants asked that their own names be used in the final written report. I had these participants choose their own pseudonyms so that they can easily identify themselves in the thesis. All living donor participants are referred to by their independent study numbers in my field notes and in the audio recordings of their interviews. Nola Johnson is the only living organ donor participant who has not been assigned a pseudonym or independent study number. I had met Nola outside of the Ottawa Hospital Renal Transplant Clinic and she agreed to the use of her real name.

My Own Experiences as a Directed Living Organ Donor:

Conducting research on the experiences of directed and non-directed living organ donors required that I examine my own experience as a directed living organ donor. However, I limit reflecting upon my own experiences as a kidney donor to the introduction of each chapter since, according to Rosaldo, “If classic ethnography’s vice

was slippage from the ideal of detachment to cultural indifference, that of present-day reflexivity is the tendency for the self absorbed Self to lose sight altogether of the culturally different Other” (Rosaldo 1989: 7). The following narrative is my own, since analyzing the narratives of directed and non-directed living organ donors compelled me to examine how I constructed the organ donation and transplantation process as a meaningful experience for myself.

When I was six years old, I used to go with my father to visit my mother in the dialysis unit at the Ottawa General Hospital. Dad and I would always bring her food. Mom was on the dialysis diet, which meant that all of her food was boiled more than once, leaving it grey and unappealing. So we would try to pick out something that we knew would tempt her appetite: a Reuben sandwich with extra sauerkraut, or pralines and cream ice cream. Even though we knew the hospital staff would disapprove, we often picked food that was high in sodium. We reasoned that it didn't matter because the sodium was filtered from her blood by the dialysis machine, taking over a function that her kidneys had once performed. It was my job to sneak the forbidden treats into the hospital. Dad was lucky that the hospital staff tended not to suspect an unassuming and innocent looking six year-old. Incidentally, I would always end up eating most of the ice cream. For my mother and many other haemodialysis patients, food tasted metallic. In addition, her freedom was limited because she had to be hooked up to a dialysis chair three days a week.

My mother received her haemodialysis treatments in a large, bright room along with many other people in various stages of kidney failure. I would often take my infant

brother and wander around the dialysis ward, socializing with nurses and making friends with patients. One of these patients was an elderly woman who had lost her grandchildren in a tragic car accident. My brother and I would often spend hours with her and she bonded quickly with us because we reminded her of her lost grandchildren. I still have the snowflake shaped doilies that she knitted for me and I often wonder what became of her. Another, rather colourful patient, was my mother's "dialysis-friend," Thor. Physically, Thor did a good job representing the god that he was named after. Looking like a real metalhead, Thor wore his blond hair long, with ripped jeans and band T-shirts. I remember how Thor always seemed ready for a laugh and how he enjoyed playing pool with the other patients. A couple of years ago, I asked my mother what had happened to Thor and if she ever kept in touch with him. She responded, rather matter-of-factly, that Thor was dead. In fact, most of the people that my mother knew while on dialysis are now dead.

My mother often felt good for the first day or so after undergoing treatment. As the week wore on, she became sick and weak, spending most of her time sleeping. When she wasn't sick or tired, my mother often became angry with herself because she could no longer perform the tasks that used to come so easily to her before going onto dialysis. She desperately wanted to take care of my little brother, but she didn't have the energy, so a home care worker would come in every couple of days to help mom out with household tasks. I also had to take on more responsibility. At six, I was often charged with watching my little brother, and sometimes that didn't go well because I did a better job watching cartoons than I did watching him. Moreover, we could not travel or go camping like we

had previously done and I would often spend the summer at the cottage with my grandparents. However, throughout her entire ordeal, my mother struggled to remain positive, which was not an easy task considering that her doctors gave her a seven percent chance of ever regaining kidney function. My mother, ever the optimist, told her doctors that seven percent was better than zero.

My mother's kidney failure was not caused by a predisposed genetic condition or by diabetes, but by giving birth to my brother. My brother was born almost a month premature. I was getting ready to go the babysitter and my father was getting ready for work, when my mother went into premature labour. When we got to the hospital, she was quickly taken away on a stretcher, as she waved goodbye to me. I was left alone to wait for my grandfather to pick me up, occasionally receiving sympathetic glances and words of encouragement from the nurses. I spent almost a month with my grandparents. I rarely saw my father because he spent all of his time at the hospital with my mother. Although I desperately wanted to visit her, I was told that children were not allowed in the intensive care unit where my mother spent the first two weeks of her lengthy hospital stay. I only got to see her once when my father thought that she was dying.

The doctors were at a complete loss in determining what was wrong with my mother. She underwent extremely painful and invasive diagnostic tests before a haematologist finally diagnosed her with a rare blood disorder called TTP (Thrombotic Thrombocytopenic Purpura), which causes blood clots, strokes and kidney failure (Kinoshita et al. 2001). Not only did my mother suffer from kidney failure, but she also suffered a series of strokes, which left her partially paralyzed. After my mother was well

enough to be moved from the intensive care unit, she had to undergo rehabilitation therapy to learn how to walk, talk, dress and cook. All of the mundane tasks that she used to perform were no longer simple, and on top of everything, the doctors were not very confident that would regain her kidney function. My mother spent nine months on dialysis and she never forgot her seven percent chance of regaining kidney function. Everyday, she would ask the doctors to test her blood, until they finally complied with her wishes. It turned out that my mother was right. She ended up regaining 30 percent of her kidney function, which she retained for 16 years.

When her kidneys began to fail in December of 2005, my father was undergoing treatment for prostate cancer and could not donate. I remembered how limited her life had been while she was on dialysis and I wanted her to have the freedom to travel and to have an unrestricted diet.

Initially, my mother refused my offer to donate because she did not want me to put my own life at risk. Moreover, as a parent, she worried that I would develop long-term health problems associated with having only one kidney. It took some convincing, but I finally persuaded her to accept my offer of a kidney.

I began the organ donation and transplantation process by contacting the living organ donor coordinator for the Ottawa Hospital. At my request, the coordinator arranged for all of my testing to take place during the summer before I had to go back to my fourth year of university in Toronto. During the summer of 2006, I was at the transplant clinic at least three days a week for various diagnostic tests, which included numerous blood samples for tissue typing. Tissue typing determines if a donor is a viable match to their

recipient, and depending on the results, whether a donor will be able to continue with the organ donation and transplantation process (The Kidney Foundation of Canada 2005). I was nervous about the tissue typing because the living donor coordinator informed me that I might not be a good tissue match, since this outcome is not uncommon for parents and offspring. In fact, according to the living donor coordinator, my mother had a better chance of finding a tissue match among one of her siblings. However, at the end of my testing, my mom and I were informed that we were almost a perfect tissue match—something very rare for parents and their children.

My mother and I were heading to a transplant information workshop when the living donor coordinator informed us that we were nearly a perfect tissue match and that I would be able to continue on with the rest of the testing. I was so relieved that I gave the coordinator an impromptu hug before continuing to the conference room where the workshop was held. The workshop began with a series of presentations targeted towards the recipients. First, the recipient coordinator described what to expect pre-and post-operatively, the potential risks and benefits of transplantation and the importance of post-operative care. Next, a middle-aged man spoke about his positive experience as a kidney recipient. He explained that he had been diagnosed with PKD (Polycystic Kidney Disease), which is a genetic disorder that causes cysts to form on the kidneys (Weening and Remuzzi 2010). He described how he had been on dialysis for a number of years before his brother offered to donate a kidney and how much his life had changed post-transplantation. Finally, he ended his presentation by describing how he had undergone a minor form of rejection shortly after the transplant. He tried to reassure the audience by

explaining how common rejection is and how the transplant team was able to prevent it through adjusting his antirejection medication.

Initially, I was inspired by his story and how easy he made the organ donation and transplantation process seem. Only later, going through the organ donation and transplantation process myself did I realize that it does not go as smoothly for everyone. After having heard from a transplant recipient, I was looking forward to hearing from a donor about their experience with the transplantation process. I was surprised and disappointed to discover that the transplant team had not asked a donor to speak at the information session.

The final speaker was a pharmacist who spoke about the types of antirejection medications that would be prescribed to recipients post-transplantation. The pharmacist concluded her presentation with a cautionary tale involving a recipient who decided not to take his antirejection medication and almost lost his kidney. The moral of the story, she told recipients, was to make sure always to take your antirejection medication. I looked around the room to see all of the potential recipients nodding their heads in agreement.

The rest of the testing went smoothly and I was able to meet with both the transplant social worker and psychiatrist before going back to university. I was nervous about meeting the transplant social worker and psychiatrist because their recommendations would determine whether I would be allowed to donate. I found the meeting with the transplant social worker to be rather short. The social worker asked questions pertaining to ownership of the kidney. My response reflected the fact that I was

comfortable with giving up ownership of the donated kidney. However, once I had left her office, I wondered how truthful my response had been.

Similarly, my meeting with the transplant psychiatrist was brief. The transplant psychiatrist was interested in determining why I wanted to donate. I thought that the answer was quite obvious. I wanted to donate, I told him, because I loved my mother. He seemed reasonably pleased with my answer. Although I was content with my decision to donate a kidney, I wondered if I had only told the transplant social worker and psychiatrist what they wanted to hear in order to continue on with the testing. Before I left for school in Toronto, the transplant team composed a letter for me to give to the faculty members of my department explaining that I would have to miss classes and delay assignments for the period when I would be hospitalized to donate. I realized that this letter now meant that my decision to donate was official and I would actually have to tell people about the transplant.

I had refrained from telling too many people about my decision to donate a kidney to my mother. It took me months to get up the courage to tell one of my closest friends that my mother needed a kidney transplant and that I was her donor. I was afraid to tell people because I did not want to deal with all of their questions. Also, I felt that once I told people, the act of donating would become real and I would have to deal with any anxieties that might arise. Up to the point of telling people, I had managed to avoid thinking about possible complications and misgivings associated with the donation. However, luckily my friends were extremely supportive throughout the whole process. My roommates even offered to drive me back and forth between Toronto and Ottawa.

Also, the living donor coordinator was very helpful and she kept in constant contact with me to make sure that I was not overwhelmed by worries.

Finally, my mother and I received the date for our surgery: December 14, 2006. I was excited to donate, but I was also nervous because I had never been under general anesthetic. I arrived early on the morning of the surgery because I was scheduled for 8:30 a.m., while my mother was scheduled for later that afternoon. I was escorted to pre-operative area to get undressed, put on the hospital gown and have my intravenous line inserted. To my intense relief, I learned that my catheter would only be inserted after I was under the anesthetic. Once I had my backless, hospital gown on, my Robin Hood tights, which are pressure stockings that prevent blood clots, and my intravenous line inserted, I was taken to the operating room. While waiting outside the operating room, I was asked by a fully gowned and masked scrub nurse to sign a multitude of hospital consent forms. However, I only became nervous when the renal transplant surgeon asked me which kidney they were going to be removing. I figured that he was just making sure that I had read the consent forms.

The operating room was small, but brightly lit with instrument trays located around a narrow operating table. Having never had surgery before, my ideas about hospital operating rooms had been heavily influenced by popular television shows such as *Grey's Anatomy*, *House* and selected episodes of *The Simpsons*. I honestly expected the room to be bigger, featuring a glass ceiling where medical students could peer down at me while taking notes. I realized that I was slightly disappointed with the reality. Once I was in the operating room, I shimmied over and onto a very narrow and cold surgical

table. My thin hospital gown did little to keep me warm and did not leave much to the imagination. My left arm was extended and strapped down while the surgical team tried to put me at ease by making small talk; however, I found it disconcerting that I could not recognize their faces because everyone was gowned and masked. I was not uncomfortable for long because I soon succumbed to the anesthetic. The last thing that I remember was counting to three.

Coming out of anesthetic is like waking up from the best night's sleep that you've ever had, but I soon realized that I was not in my safe, comfortable bedroom and that realization left me feeling very disoriented. The disorientation faded as the oxygen took effect and I began to wake up. However, being fully awake meant that I could feel the sharp, throbbing pain from my incisions, which was promptly treated by the recovery room nurse and her syringe full of blissful pain medication.

The recovery room at the Ottawa General Hospital is a large room, which is surprisingly quiet as everyone speaks in whispers so as not to disturb the sleeping patients. As soon as I was fully awake, a recovery room nurse came over with more consent forms. While going through admission, I had signed a form stating that I was eligible to receive a morphine pain pump. I was excited because a pain pump would allow me to control my own medication without having to rely on the overworked nursing staff. I also felt that the recovery room nurse was being a bit stingy with the meds and I got tired of rating my pain on a scale of one to ten. The only problem was that the nurse could not find the consent form indicating that I had signed for the pump. It was at this point that I cried for the second time during the whole organ donation and transplantation

process. The first time that I cried was when I was informed that I might not be a suitable donor match. So, I informed the nurse that I had, in fact, signed for the pain pump. A couple of minutes later, although it felt like an eternity, she found the missing paper work and I got my very own morphine pain pump, which kept me thoroughly entertained for the first 24 hours of my brief hospital stay.

I was in the recovery room for most of the day because my semi-private hospital room was not ready. Once my room was ready and before they took me up, I was able to see my mom. My mother's surgery had taken place around noon and two hours later she was brought to an isolated part of the recovery room, away from the rest of the patients. The recovery room staff kept my mother in isolation in order to protect her now compromised immune system from secondary infections. So, my mom spent the first 24 hours in recovery, where she was closely monitored by the recovery room nurse and where we had a brief post-operative reunion.

Mom was slightly disoriented from the medication; she was swollen from surgery and she had an intravenous tube protruding from the side of her neck. Although she was experiencing some discomfort, she was extremely happy and relieved that the whole process was finally over and we could recover together. Our brief reunion was very emotional. We smiled at each other and she thanked me for the kidney. I felt really good knowing that I had been able to help extend her life; however, I was not prepared for how emotionally exhausting the recovery process would be. At that point, I was just content that the procedure was finally complete and that I could concentrate on getting on with the rest of my life.

After visiting with my mother, I was moved from recovery to a semi-private room. My roommate was the mother of the nurse who used to look after me as a baby in the neonatal unit of the Ottawa Children's Hospital and it was a comfort to have her around. My first night in the hospital passed rather uneventfully. I did not sleep very well because I could not seem to get comfortable and the nurse came in every hour to check on me. When I did manage to fall asleep, I would awaken to people screaming and moaning. The ward that I was on had patients suffering from dementia and they tended to regress at night, which was very unnerving. I passed much of that first night in the hospital chatting with the nurse and seeing how many times I could press the button on the morphine pump before the failsafe cut off the flow.

In the morning, a new nurse came in to take a blood sample. The other patients referred to her as the vampire lady. She was rather abrupt, turning on the light so quickly that it was temporarily blinding. After the vampire lady, the day nurse arrived with my daily shot of heparin. Although I needed to have the shots twice a day, I found them to produce an unpleasant burning sensation. The nurse administered the shot in my stomach, near my incisions. Finally, I was given breakfast, which I eagerly anticipated because I had not eaten in a couple of days. To my intense disappointment, breakfast consisted of the liquid diet, which featured an unappetizing hospital jello, beef broth and ginger ale. I decided that the safest way to go would be to stick with the jello and ginger ale. I longed for solid food, which I was denied until my bowels started working again. After breakfast, a doctor and his coterie of medical students arrived to see how I was progressing. The doctor and his students stood around my bed and looked at my incisions

collectively deciding that I should remain on the liquid diet and that I no longer needed my morphine pump. In order to pass the time without the aid of my morphine pump, I began to take short walks to visit my mother.

My mom was kept in a private room in order to recover because her immune system was weak and she needed time to adjust to her antirejection medication. During the first few days after the surgery, she was doing rather well and the kidney was functioning normally. I spent a small amount of time in her room because I was weak from the surgery and the lack of food. Also, the pain medication that I had been given after the morphine pump was discontinued made me sick to my stomach. Moreover, I was extremely uncomfortable during my second night in the hospital. I could not sleep because I was sick to my stomach and the screaming and moaning from the other patients got progressively louder and more insistent as the night wore on. Finally, on the morning of the third day, I was feeling much better. During the night, I had asked that my medication be changed to something that I could tolerate. I was also placed on solid food, which consisted of a pudding cup—a small victory since I would no longer have to eat the jello.

I was discharged from the hospital in the afternoon, three days after the surgery. It is typical for kidney donors to spend only three days in the hospital after surgery and I was very eager to leave. As a recipient, my mother would have to stay in the hospital for a couple of weeks to recover and I was sad to leave her behind. However, I looked forward to spending time with her while we both recovered. Little did I know that her recovery time would be more extensive than we had initially expected.

I had been recovering at home for a week when my mother phoned to tell me that the transplant team thought that the kidney was dead and was discussing its possible removal. We were both devastated by the news because her recovery had been going so smoothly that we had never considered the possibility of rejection. Moreover, the transplant team had reassured us that the possibility of rejection was minimal because of our strong tissue match. I do not really remember the rest of that conversation. I do remember feeling like I had somehow failed my mother and that it was my fault that she was rejecting the kidney. I sat down on our living room couch, where I had been spending my days since returning home from the hospital, and I cried for the third time since going through the organ donation and transplantation process. Paradoxically, my mother also felt as if she had failed me and that her body had somehow intentionally rejected the kidney. We were both left desperately wondering what we were going to do.

I went to the hospital that afternoon to visit my mother and to discuss our options with members of the transplant team who had mentioned the possibility of removing the organ. My mother's last biopsy had indicated that the kidney was necrotic, however, one of the surgeons was adamant that another biopsy be performed before the final decision was made to remove the organ. Therefore, we eagerly awaited the tests results of the final biopsy, which would determine my mother's and her new kidney's fate.

The final tests results from the biopsy determined that the edge of the kidney was necrotic, but that the middle of the kidney was still viable. The decision was made to treat my mother's rejection and she underwent plasmapheresis in order to remove the antibodies from her blood that were attacking the kidney. Plasmapheresis is used to treat

immune disorders through the, "...separation of plasma from blood cells, and reinfusion of cells plus autologous plasma or another replacement solution" (Madore 2002: 375-376). My mother's new kidney was saved through her determination to keep the organ, by the active efforts of the transplant team and by one special renal transplant surgeon who knew how much that little kidney meant to us.

I found the whole organ donation and transplantation process to be a very rewarding and yet emotionally stressful experience. The transplant team was very efficient and the living donor coordinator was very supportive. The living donor coordinator worked hard at making sure that all my diagnostic tests were booked during my vacation from university and she always made time to answer the questions that I had about the transplantation process. However, while going through the organ donation and transplantation process, I began to notice some discrepancies. For instance, while I was told that I would need to factor recovery time into my schedule, I came across stories of donors going back to work immediately after donating. Other discrepancies included the inability of the hospital staff to facilitate meetings between donors. I realized that I did not know any other living donors. In fact, the only time that I encountered another donor was while I was recovering in the hospital after the transplant. The donor that I met also expressed concern over the fact that she had been unable to interact with other donors. I wondered why the hospital did not facilitate a support group for donors as it does for recipients. I was interested in meeting with other donors in order to determine how they felt about the organ donation and transplantation process. First, I had to determine where I could meet donors outside of the clinical setting.

In October of 2008, I received a rather formal invitation to attend an organ donor gala hosted by the Ottawa Hospital Renal Transplant Unit. I was excited to attend the gala because it would be an opportunity to network with other kidney donors. My family and I arrived at the Civic Campus of the Ottawa Hospital early in order to find the room where the gala was being held. The living donor coordinator and the recipient coordinator greeted us as we made our way into the lecture theater where the main part of the organ donor ceremony was to take place. Once we found our seats, I looked around and recognized the faces of members of the transplant team, and many other organ donors like myself waiting for the ceremony to begin.

An elderly gentleman, dressed in a suit and red, polka-dot bow tie, stood and walked over to the podium to give the first presentation of the evening. The quirky looking man introduced himself as Dr. Dossetor and I soon discovered that he had been instrumental in the development of nephrology in Canada. In fact, Dr. Dossetor had solidified his career by performing the first kidney transplant in Canada in 1958, between identical twin girls. Dr. Dossetor gestured towards a photo of Nola Johnson who had generously donated one of her kidneys to her twin sister. I recognized her as one of the two women with whom we had walked into the gala. I had actually been standing in front of the first kidney donor in the Commonwealth and I hadn't even realized it! Nola Johnson's role as a kidney donor was the catalyst in the development of nephrology in Canada.

Next, a recipient gave a brief presentation describing how his brother's willingness to donate a kidney had saved his life, which was followed by a presentation

given by the head of nephrology for the Ottawa Hospital Renal Transplant Clinic and a member of the Trillium Gift of Life Network. Once again, I kept expecting that a kidney donor would be called upon to share their story and was sorely disappointed when one did not materialize. After the presentations concluded, each organ donor was presented with a medal, which had the donor's name engraved on the front and the inscription "Gift of Life," on the back. Unfortunately, not all of the medals that were presented to donors that night had a happy ending. I watched as an older woman walked up to the stage and claimed her medal; her recipient had rejected the organ and had passed away. My medal sits on my bookshelf, still in its original green box.

After the ceremony, all the organ donors and their families gathered in the lobby to socialize. I had the opportunity to meet Nola Johnson and I have to confess that I was rather shy. However, I soon realized that Nola was just as shy and I felt very comfortable in her presence. I explained to her that I was an M.A. student at McMaster University, and that I was conducting research to explore why living organ donors decided to donate their kidney to a loved one. Nola readily agreed to participate in my research and I was excited to be able to have the opportunity to interview the first kidney donor in Canada. I met a couple of other donors and I reconnected with the living donor coordinator and my transplant nephrologist who were very supportive of my research endeavour. I left the gala convinced that I would soon be conducting research at the Ottawa Hospital Renal Transplant Clinic, a place that I had not visited since donating my own kidney.

Chapter II

“Share Your Spare:” The Experiences Of Directed and Non-Directed Living Organ Donors in the Ottawa Hospital Renal Transplant Clinic.

It was a warm day in July when I exited the fifth floor elevator and made my way to the front desk, which dominates the entrance of the Ottawa Hospital Renal Transplant Clinic. The Ottawa Hospital Renal Transplant Clinic was created in 1998 when the Riverside Hospital, which had been a fully functioning hospital, became part of the Ottawa Hospital (The Ottawa Hospital Foundation 2010). The Ottawa Hospital consists of three campuses: the Ottawa General Hospital, the Ottawa Civic Hospital, and the Ottawa Riverside Hospital (The Ottawa Hospital Foundation 2010). The narratives of directed and non-directed living organ donor participants indicate that most underwent transplant surgery at the Ottawa General Hospital or the Ottawa Civic Hospital.

I stood behind the red line waiting to check in for my appointment with a transplant nephrologist. I had begun fieldwork a couple of weeks previously at the beginning of June and I had interviewed quite a few directed and non-directed living organ donors. I enjoyed the interview sessions and sharing my experience with the other donors. However, I found it strange that almost every participant I met with asked about my kidney function. Participants would appear incredulous when I explained that I had not had my kidney function checked since I donated three years ago. I felt compelled to constantly tell participants that I intended on making an appointment with my family doctor to have it checked soon. Eventually, one participant mentioned that “my

nephrologist was my nephrologist and my family doctor was my family doctor,” meaning that I should see a nephrologist when I had questions about my kidney function and my family doctor for general health questions. After concluding my interviews for the day, I went to find the living organ donor coordinator to see if I could book an appointment with a nephrologist to have my kidney function assessed:

Throughout the organ donation and transplantation process, staff at the Ottawa Hospital Renal Transplant Clinic act as gatekeepers, determining who is medically suitable to donate a kidney (Fox and Swazey 1974, 1992). However, the Ottawa Hospital Renal Transplant Clinic encourages both directed and non-directed living organ donors to ask questions regarding the organ donation and transplantation process. Furthermore, the Ottawa Hospital Renal Transplant Clinic advises donors to research the risks and benefits of living organ donation and to negotiate with the transplant staff about dates for testing and the transplant. Through education, directed and non-directed living organ donors become active participants in the medical encounter with the Ottawa Hospital Renal Transplant Clinic. However, upon completing the organ donation and transplantation process, directed and non-directed living organ donors can spend up to a week recovering in the hospital (The Kidney Foundation of Canada 2005). Therefore, the autonomy that directed and non-directed living organ donors enjoyed at the Ottawa Hospital Renal Transplant Clinic is reduced by the controlling, bureaucratic, hierarchical nature of the Ottawa General Hospital, or the Ottawa Civic hospital where they go for surgery and recovery. A once active donor becomes passive and compliant. Following Deborah Lupton’s (1995: 114-115) argument that participants become active members in the

medical encounter through education, which balances out the power relations between doctor and patient, the first part of this chapter focuses on how directed and non-directed living organ donors become active members of the organ donation and transplantation team at the Ottawa Hospital Renal Transplant Clinic. In turn, using Scheper-Hughes' and Lock's (1987) concept of the body politic, which speaks to power and control within biomedicine, the second part of this chapter discusses how directed and non-directed living organ donors become passive, docile bodies while recovering, post-operatively, in the hospital (Foucault 1977, 1989; Scheper-Hughes and Lock 1987).

Since she was the first kidney donor in Canada, Nola Johnson's narrative speaks to the changing nature of the transplant clinic, the hospital experience and the relationship between physician and patient. Nola Johnson's narrative reflects a rather positive hospital experience. Furthermore, Nola Johnson and her primary care physician, Dr. John Dossetor, formed a lifelong friendship upon the completion of the organ donation and transplantation process. In contrast, the narratives of the nephrologist and living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic, Dr. Anderson and Lisa, reflect the evolving dynamic between doctor and patient. For instance, Dr. Anderson is rethinking the risks associated with directed living organ donation, which he calls the "grey zone of transplantation."

Nola Johnson:

I interviewed Nola Johnson and her younger sister Lynne on a cold and rainy summer afternoon in June. I was looking forward to seeing Nola and Lynne again because I had last seen them seven months previously at the living organ donor gala. Nola

Johnson is a soft-spoken, positive and rather shy woman. In contrast to Nola, Lynne is more outgoing. However, both women were very welcoming and I instantly felt at ease when I entered their west end Ottawa home. Nola brought me into the kitchen where we were to conduct our interview. Lynne joined us a short time later and contributed to the conversation by substantiating and adding to Nola's memories of donating a kidney to her twin sister, Moira. Nola and Lynne both grew up as part of a large, close knit Irish family living in Montreal. Nola and Moira, who passed away from cancer in the late 1980s, worked at Reader's Digest. Nola worked in the marketing department on the condensed book and music series before deciding to take early retirement, because she found that the work had become too political and hectic. Nola described herself as being just as shy as she is today. When she was a teenager, she enjoyed going to school, playing sports and she shared a close bond with her twin sister, Moira. At the age of fifteen, Nola Johnson became Canada's first kidney donor when she successfully donated a kidney to Moira.

In March of 1958, Moira became violently ill and the family rushed her to the Montreal Neurological institute where, according to Nola, "they determined that she had a kidney problem, they moved her over to the Royal Victoria Hospital, right next door. They did all sorts of tests and then they discovered that she was a twin." Once the doctors at the Montreal Neurological Institute found out that Moira had a twin, they became very interested in Nola and the prospect of kidney transplantation. "[O]ne of the doctors was very interested because he knew about transplantation of kidneys. At that time it was only done a few times before that." Although kidney transplantation was still a revolutionary procedure, it was not a new concept: the first successful kidney transplant occurred in

1954 in Boston between identical twin girls (Scott 1981). Especially interested in the twin's case was Moira's primary care physician, Dr. John Dossetor (2005), who would later write that meeting Nola and Moira Johnson not only changed the trajectory of his career, but also helped to establish nephrology in Canada.

Interestingly, although Moira's physicians were interested in Nola as a potential kidney donor, they did not approach her directly. Instead, the doctors met with Nola's mother about the possibility of donation.

I remember my mother had a meeting with the doctors: the doctors wanted to meet with my mother for some reason and it sounded quite serious. As we were coming out of the hospital—I wasn't involved in that meeting—we were coming out of the hospital and she told me that Moira was very ill and that she wasn't going to live. But she said that the doctors were telling her about transplanting a kidney and I jumped in right away because I had read in the paper, a few weeks before, about one of the transplants. And I said, 'I will do it...I will donate a kidney.' My mother didn't even have to ask me, I jumped in before. So, at that point, my mother went and told the doctors...and they were thrilled...because this was something...they didn't like to ask...

Today, at the Ottawa Hospital Renal Transplant Clinic directed living organ donors meet with the living donor coordinator whose role, within the Clinic, is to determine whether or not the donor wants to donate or is being coerced by family members into donating. However, because Nola Johnson was the first kidney donor, her mother took on the role of living organ donor coordinator, representing Nola in meetings with the doctors.

Once Nola decided to become her sister's donor, she underwent various diagnostic tests in order to determine that she was an identical twin and that she had two functioning kidneys. During the testing, Nola interacted quite closely with the doctors, spending most of her time in the lab.

I was in the lab for hours and hours at a time...making sure that my kidney was functioning properly. They checked our earlobes and everything to prove that we were identical...those are the ones that I remember...sitting in the lab. And I was in there for hours...drinking lots of water...they didn't do it by blood tests...they did a lot by your urine...I would sit there and drink, drink, drink...and it ended with a blood test...now they do so much blood work...

Nola continued her narrative by describing the testing that she had to undergo to make sure that she was in fact an identical twin the doctors contacted a geneticist:

He checked me out for all sorts of things...they had to be very careful, I guess, to make sure. I just remember them checking my ears, and my nose and different things on my head. And, I thought, 'Why are they doing this?'...They made all the preparations for—not that I knew what was going all—I had to do all sorts of tests for my kidney. I was thinking of making Moira OK. That was my main concern. I didn't think about myself...

Finally, Nola described how the physicians performed a skin graft and she rolled up her sleeve to show me explaining that “They did a skin graft; I have a bit of Moira’s skin on my arm here: a skin graft from one to the other...and it took. It wouldn’t take on anybody who wasn’t an identical twin. So that really solidified everything...”

Once Nola was declared to be a fit donor, her physicians discussed the appropriate location for the surgery. The transplant team decided that Boston was the logical choice since that is where the first successful kidney transplant had been performed (Dossetor 2005). However, Nola’s mother felt that Boston was too far for the family to travel and as Nola explains her mother did not want to leave the rest of the family behind.

So then they wanted to know if we wanted the operation done in Boston because that's where the other ones had taken place...but my mother didn't want to leave the family because she had lots of younger ones and she didn't want go down there...she said that they have good doctors here in Montreal: a couple of them went down and prepared...did some preparation down there. The operation took place on May 14, 1958.

For the first time since the beginning of the organ donation and transplantation process, Nola Johnson's mother took an active part in the process by refusing to move Nola and Moira to Boston. However, Nola still remained a rather passive participant in the organ donation and transplantation process, although her narrative on her hospital experience reflects a generally positive medical encounter.

The hospital where Nola recovered after her surgery was bustling with students and Candy Strippers, volunteer visitors, so named because of their red and white striped uniforms. Nola explained that many people were interested in the twins' story, which brought many people to her hospital room. In order to protect her privacy, the hospital staff moved Nola to the men's ward, which protected her from overly curious members of the public.

We were kept on the men's floor...they hid us away towards the end of the men's floor. A few days before I was due to be released, they put me into the other end with the women. The article was coming out in the newspaper, just before I came home from the hospital...got a lot of interested people coming to look in my room.

After the highly successful procedure, Nola spent ten days in the hospital recovering from surgery and, unlike many of my other living organ donor participants, Nola described a largely positive hospital experience, which she attributed to an attentive staff. For instance, Nola explained how the nurses were very vigilant, making frequent rounds and constantly changing the bedding. "I know that they left the intercom on because my room was right next to the nurse's station. They left the intercom on so they could hear me." However, Nola's rather lengthy hospital stay resulted from the fact that the minimally

invasive laparoscopic surgical procedure now used for removing donor kidneys was not available at the time when she donated. Nola described how her scar was quite long and how it extended all the way down her back. “[M]y incision went from down my back, all the way to my front...they made it extra large...that was healing and that’s all I felt...”

In contrast to Nola, Moira spent more time in the hospital, undergoing more surgery to remove her two non-functioning kidneys. After Nola was discharged from hospital, her doctors instructed her to be careful to avoid damage to her remaining kidney, which meant that Nola had to refrain from playing contact sports, something that she had enjoyed prior to the transplant. Once both Moira and Nola returned home from the hospital, family members made sure that the twins followed their physician’s instructions. Lynne, Nola’s younger sister, told me that she and other family members would make sure that Moira was careful not to bump her new kidney. Lynne stated that, “We were very protective of Moira in case she got hit or bumped into things or something...” Finally, Dr. Dossetor maintained a friendly, lifelong relationship with Nola and her family after the transplant. Nola explained during our interview that she still sees Dr. Dossetor on a regular basis and that he continues to visit her: “Actually, I was speaking to their daughter who is a dermatologist and her parents go to visit my mother in the nursing home.”

As Nola’s story illustrates, she had a generally positive post-operative hospital experience. However, Nola still remained a passive participant in the organ donation and transplantation process as she was subjected to diagnostic testing in order to determine that she was an identical twin. Moreover, Nola formed a lifelong friendship with her

primary care physician outside of the hospital setting, which is uncommon between organ donors and their physicians. Nola Johnson and Dr. Dossetor exhibit a positive doctor-patient relationship, which transcends the boundaries of the clinic. Nola's positive experience in the hospital may be related to the fact that she was the first kidney donor in Canada and the process was experimental. Now the process has become routinized along with the doctor-patient relationship, which does not transcend the boundary of the Ottawa Hospital Renal Transplant Clinic. Turner's (1969) concept of liminality applies to the relationship between Nola, Moira and Dr. Dossetor, since they were "betwixt and between" the period when transplants were unknown and the period when they became routinized. One of the features of liminality is the development of close, personal relationships: *communitas*, which transcend social hierarchy (Turner 1969). In Nola Johnson's case, she formed a personal and long lasting bond with Dr. Dossetor. The next section will examine how members of the transplant team at the Ottawa Hospital Renal Transplant Clinic, mainly the transplant nephrologist and the living organ donor coordinator, evaluate potential living organ donors. I will also discuss donor health states, the doctor-patient relationship and what Dr. Anderson refers to as "the grey zone of transplantation."

Transplant Nephrologist:

Dr. Anderson is a transplant nephrologist at the Ottawa Hospital Renal Transplant Clinic. Dr. Anderson describes himself as physician specialist who takes care of people that have been diagnosed with kidney disease. Along with looking after those who are afflicted with kidney disease, Dr. Anderson evaluates potential living organ donors and

helps to determine if they are medically suitable to donate a kidney. I interviewed Dr. Anderson in his office, which is located on the fifth floor of the Ottawa Hospital Renal Transplant Clinic.

I found Dr. Anderson to be very candid throughout our interview and I was surprised with how much he shared about the doctor-patient relationship and how concerned he is about paternalism in medicine. We spoke for some time about the criteria for evaluating living organ donors, donor health states, the benefits and trends of living organ donation and the paternalistic nature of the doctor-patient relationship. Ultimately, Dr. Anderson cares about his patients and wants to make sure that all of them make well-informed decisions regarding their primary health care.

According to Dr. Anderson, the most critical part of the organ donation and transplantation process “is the post-operative assessment and management of people who have donated kidneys.” Dr. Anderson explains that he believes that educating living organ donors on the organ donation and transplantation process is key to making an informed decision and helps to reduce coercion:

I think that is a key issue and trying to inform individuals about kidney donation and it's something that we struggle with because I do go through a series of discussions with each patient about risks and benefits of donation. So we go through short-term and long-term risks and we talk about the risk to the donor, the risk to the recipient. So, I talk a lot about the donor risks—about the surgery and what happens around the surgery...what happens right after the surgery...what happens in the first four weeks...and I talk about pain and pain control...and I talk about the fact that the remaining kidney will grow and take over the function partially of the lost kidney and what that means...and that one can live normally with a single kidney and why...the long-term risks and then the benefits...so, I talk to them about the potential benefits of kidney donation...

Through education, reading and asking question about the organ donation and transplantation process, directed and non-directed living organ donors become active participants in the medical encounter (Lupton 1995). Therefore, Dr. Anderson recommends that potential directed and non-directed living organ donors research the organ donation and transplantation process on the Internet and he encourages donors to ask as many questions as possible while making informed health care decisions.

Next, Dr. Anderson explains that he makes sure that potential directed and non-directed living organ donors are aware of the risks of transplantation and surgery:

I mean, I always look at kidney donation as a surgery that someone doesn't need. The first thing often asked is what are your chances of coming out of the operating room alive. It sounds very crude, but the success rate is very high: in something like 3 out of every 10,000 surgeries is there a death and that is .03 percent. That mortality rate is comparable to many other surgeries...

Once Dr. Anderson establishes that the donor's questions regarding the risks and benefits associated with the organ donation and transplantation process have been answered, the donor undergoes a global health assessment. The global health assessment, according to Dr. Anderson, makes sure that the donor participant is healthy enough to part with their kidney. So, a living donor candidate will undergo a series of diagnostic tests in order to determine "that other health areas would not be adversely affected by kidney donation." These tests help to assess what Dr. Anderson refers to as the "grey zone of transplantation": the risks that are acceptable in order to allow a person to donate to a loved one.

The Grey Zone of Transplantation:

Dr. Anderson describes what he calls the grey zone of transplantation, which encompasses the issues of risk, donor health and the paternalistic nature of the doctor-patient relationship. In order to explain the grey zone of transplantation, Dr. Anderson refers to a hypothetical situation in which:

There is a potential donor and a recipient and let's take an example of a husband and a wife; say the husband is on dialysis and the wife comes forward and wishes to donate a kidney and we find something in the wife's health that normally would preclude her from being a donor according to the guidelines. The wife says, 'Listen, our marriage is dependent on the quality of our lives, and right now that quality is so poor with my husband on dialysis that I'm willing to do just about anything to give him a kidney and I'm willing to accept the risk even though I know that you're telling me that my health is going to be affected.' This is the grey zone of donation that I think is an important grey zone.

Negotiating within the grey zone of transplantation means rethinking the power dynamics of the doctor-patient relationship and of the organ donation process. Dr. Anderson questions his authority over potential donors who understand the risks and yet still want to donate. He asks himself whether he should refuse to accept kidneys from donors like the wife in his hypothetical case.

The narrative of Lisa, the living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic, addresses the issue of collaboration between the Clinic and potential living organ donors.

Living Donor Coordinator:

I first met Lisa, the living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic, when I decided to donate to my mother. Initially, as a new prospective

donor, I phoned Lisa to get more information on living organ donation. On the phone, I found Lisa to be very personable. She asked a series of questions beginning with my blood type and concluding with a brief medical assessment.

Lisa is compassionate toward potential living organ donors and their family members. Lisa's position as living donor coordinator was created in 2006 as a way to ease the workload of the recipient coordinator who, at that time, was responsible for looking after both donors and recipients. Before becoming the living donor coordinator, Lisa worked in the deceased donor program helping to procure organs for transplantation. Lisa enjoys working with potential donors and the collaborative approach of working with the other members of the transplant team. I interviewed Lisa in her office at the Ottawa Hospital Renal Transplant Clinic.

According to Lisa, the organ donation and transplantation process begins when a patient, undergoing dialysis treatment, becomes eligible for a transplant. Next, the eligible candidate is asked by the living organ donor coordinator if they have a potential donor. If the patient does have a potential donor, the patient is given the living organ donor coordinator's card with her contact information, so that the donor can contact Lisa. Lisa stipulates that the recipient is not encouraged to call the living organ donor coordinator. On occasion, some recipients have called claiming to have a potential donor. Lisa explains that the donor must come forward and contact her directly to avoid appearing as if the program is soliciting organs from unwilling donors.

When a potential donor contacts Lisa, it is her job to provide them with as much information about living organ donation as she can. Moreover, Lisa schedules many of

the diagnostic tests that living donors undergo and she provides emotional support for donors. She describes the living organ donor program at the Ottawa Hospital Renal Transplant Clinic as innovative and privileged because the Ottawa Hospital views kidney donation as a priority program. As she explains:

We're also very fortunate, because the Ottawa Hospital considers kidney transplant to be a priority program. So with that we have been able to fast track our donors through the evaluation process. Our goal within the evaluation process is that any potential donor that comes forward, who is compatible with their recipient, that their evaluation process takes anywhere from three months to six months.

Furthermore, the transplant clinic works closely with living organ donors to schedule the testing to minimize inconvenience to the donor.

The living organ donor is able to negotiate with Clinic staff about when testing will take place. For instance, Lisa explains how:

People may be able to complete their assessments in a couple of months, but based on their professional obligations, or their family commitments timing wise, they have an opportunity to indicate to the living donor program when the surgery could take place: some people are school teachers, some people prefer it during the summer...some prefer it not be during the summer.

Many donors tend to be very vocal over the scheduling of their tests, since many have professional and personal commitments.

Once it has been established that the donor and the recipient have had a conversation about living organ donation, the donor undergoes a health assessment, according to Lisa, in order to determine “whether they are in general good health, what their height and weight is, so we can determine what their body mass index is.” Lisa explains that donors are given as much information as possible and are told that they may

withdraw from the donation process at any time. The right of the donor to withdraw at any time during the organ donation and transplantation process is mentioned in almost every conversation that the living organ donor coordinator has with a potential donor. The reiteration of this right is another way in which the transplant team tries to prevent coercion in the organ donation and transplantation process. If a donor decides that they do not want to continue with the evaluation process, the transplant team either informs the recipient that the donor is unable to donate because of a medical reason, or, depending upon the relationship between the donor and the recipient, the living organ donor coordinator will encourage the donor to speak directly with the recipient. The transplant team will provide the recipient with an “excuse” to avoid donation through the explanation that the donor is not medically suitable to donate.

In order to further educate potential donors, the living organ donor coordinator provides donors with an information booklet on kidney donation. Lisa asks that potential donors read the material and write down any questions that they may have so that she can answer their questions and ask them if they want to continue with the donation process. Next, donors go through the cross-matching tissue typing test to make sure that they are compatible with their recipient.

Living donors first become active members of the organ donation and transplantation process by initiating contact with the living organ donor coordinator. Next, many living organ donor participants will negotiate with the living organ donor coordinator and other transplant staff in order to schedule testing and surgery. Furthermore, living organ donors are encouraged to educate themselves by reading the

material provided and to ask as many questions as possible. While early transplant narratives published by Fox and Swazey (1974, 1992) depicted an imbalance of power between directed living organ donors and the transplant team, it seems that directed and non-directed living organ donors within the Ottawa Hospital Renal Transplant Clinic are now more actively included in the organ donation and transplantation process.

We have listened to the voices of Clinic staff—the donor coordinator and nephrologist. At this point, I will discuss the narratives of several living organ donors who recount their embodied experience of being active participants within the Ottawa Hospital Renal Transplant Clinic and passive bodies during the recovery process as patients of the Ottawa General Hospital, or the Ottawa Civic Hospital.

Gary:

Generally, many of the narratives of living organ donors express a positive perspective on their experiences within the Ottawa Hospital Renal Transplant Clinic. While undergoing testing within the Clinic, many donors were able to take an active role in the organ donation and transplantation process. Usually, living organ donors asserted their autonomy by negotiating with the transplant team over the scheduling of tests and the transplant surgery, in order to minimize the disruption to their personal lives and careers.

Gary, a professional consultant from Montreal, donated a kidney to his niece in the summer of 2008. As Gary explained to me while sitting in the living organ donor coordinators' office one afternoon in early June 2009, he donated a kidney to his niece because he loves his brother. Gary was not particularly close to his niece, but when her

father, Gary's brother, found out that he himself was not a good match, Gary offered to donate. In fact, Gary's wife also offered to donate, but Gary was the best match and therefore the better candidate.

Gary does not like to speak very often about his experience as a directed living organ donor. In the beginning, Gary used to be more open and willing to speak about his donor experience, but he began to notice that people reacted in a "calculating way" in response to his narrative. For instance, when Gary told people that he was donating a kidney to his niece, they responded very positively. Next, Gary would tell them that it would be the last time that his niece would be able to receive a kidney transplant and that the kidney would only continue to function for 15 years. Upon learning that a transplant might only last 15 years, people would begin to question Gary's decision to donate. Gary explained that the knowledge that a kidney transplant does not last forever seems to make people less inclined to donate. In fact, this view was expressed by many of the people that Gary told, so he simply stopped telling people that he was donating a kidney. Gary's donation experience was very positive. However, he had to be very vocal when negotiating a date for the transplant surgery.

Although Gary was more than happy to donate a kidney, he described feeling apprehensive because of the fact that he is a self-employed consultant. Gary explained that he had to be assertive in order to have the transplant take place during a period when his business would be slow: "So, I had to put some pressure on the system to be operated on at the beginning of the summer because if I was operated on in September, then, I would have lost maybe half a year's salary." Donating a kidney in September would have

been a physical and a financial worry for Gary. He wanted to eliminate that worry by having the surgery in the summer: “It has got to be before summer time, they had to change holidays with some specialist and everything to get the job done.” The transplant clinic was very accommodating and Gary was able to donate in the early summer. Gary exercised his autonomy with regards to his health care by negotiating with the transplant clinic over the date of the surgery and ensuring that he was an active participant in the medical encounter with the Ottawa Hospital Renal Transplant Clinic.

Carrie:

I was fortunate to be able to interview Carrie about the organ donation and transplantation process when she was at the initial stages of the process as a potential new donor. Carrie was hoping to donate a kidney to her husband and had come to the Ottawa Hospital Renal Transplant Clinic for final blood work before the transplant. Carrie was accompanied to the clinic by her mother and she also participated in the interview.

Carrie was preparing to donate a kidney to her diabetic husband who had been on peritoneal dialysis for a number of years. Carrie was already familiar with organ donation, since her younger brother had been tragically killed in an accident and the family had made the decision to donate his organs. For Carrie, the issue of donating a kidney arose when she began to notice how limiting dialysis was for her husband especially when they travelled to Florida. In fact, early in our interview Carrie recounted a harrowing experience driving to Florida when her husband’s nephrostomy tube

malfunctioned and was not draining properly.¹ When they pulled into a rest room in Georgia, Carrie realized that she would have to clear the tube in order to correct the problem. Carrie was successful in her attempt at clearing the tube, and the ordeal solidified her decision to donate a kidney.

Along with Carrie, her husband's adoptive daughter had also expressed interest in donating a kidney. However, while the adoptive daughter was going through the testing, it was determined that she had four large arteries attached to her kidney. The Ottawa Hospital Renal Transplant Clinic, according to Carrie, was reluctant to operate on someone with four arteries because of the increased risk to the donor. Carrie explained that the transplant team wanted her husband to consider another donor, other than his adoptive daughter, but he refused. So, when Carrie accompanied her husband to a meeting with one his doctors, she made the active decision to be considered as a potential donor.

When I interviewed Carrie, she was days away from finding out the date of her surgery and she was excited to finally complete the organ donation and transplantation process. Moreover, Carrie explained that her experience, as a patient of the Ottawa Hospital Renal Transplant Clinic, had been very positive. Carrie's tests were scheduled very quickly and she explained that everyone had treated her very well.

Everyone, it's just been a great experience; yeah, you're always going for blood work or you're always doing your urine samples, but everybody has just been...I don't have a negative thing to say. I mean if someone

¹ A nephrostomy tube is located between the kidney and the skin, which allows for the proper drainage of urine. The tube can also be used as a "portal for minimally invasive procedures" (Saad et al. 2009: 172).

*came to me, thus far, wanting to know if this is something they should do
I would so far recommend it.*

As a directed donor, Carrie exercised her autonomy as a patient of the Ottawa Hospital Renal Transplant Clinic by refusing the Clinic's suggestion that she reconsider donating a kidney to her husband. Moreover, she exercised autonomy by insisting that her husband accept her as a donor. Like directed living organ donors, non-directed living organ donors also take an active role within the organ donation and transplantation process by negotiating testing and transplant dates.

The Ottawa Hospital Renal Transplant Clinic performed its first living unrelated kidney transplant in 1997 (Organ and Tissue Donation Program A). At the time of the first unrelated transplant, unrelated kidney donors included: spouses, close friends, in-laws and co-workers (The Kidney Foundation of Canada 2005: 29). Today, according to Lisa, the living organ donor coordinator, the Ottawa Hospital Renal Transplant Clinic also accepts anonymous, or non-directed living organ donors. These donors, according to Lisa and Dr. Anderson, do not know their recipient.

According to Lisa, the living organ donor coordinator, many in the transplant community view non-directed living organ donors as a very special group of people, because of the fact that they are donating anonymously and are not emotionally attached to a recipient. As result, the Ottawa Hospital Renal Transplant Clinic tends to be suspicious of the motivations behind non-directed living organ donors' decisions to donate. Elizabeth, a non-directed living organ donor, had to be very persistent with the Ottawa Hospital Renal Transplant Clinic when she decided to donate a kidney. Elizabeth's narrative reflects her determination to convince the Ottawa Hospital Renal

Transplant Clinic that she was serious about becoming a non-directed living organ donor, while her decision to donate encouraged the Ottawa Hospital Renal Transplant Clinic to include a new protocol for evaluating non-directed living organ donors.

Elizabeth:

Elizabeth was the first non-directed living organ donor at the Ottawa Hospital Renal Transplant Clinic. A retiree of the Federal Government, Elizabeth first decided that she wanted to donate a kidney after reading a story in the Globe and Mail about Jenny Oad and Mike Fogelman (Hartley 2009). Jenny Oad, a successful writer, donated a kidney to Mike Fogelman after meeting him on a controversial Internet site called Living Donors Online (Hartley 2009). Elizabeth explained that after reading Jenny's story in The Globe and Mail, she had her "eureka moment", thinking that she could donate a kidney.

Elizabeth had no idea about how to become a non-directed living organ donor. At first, she advertised on Living Donors Online. Soon after posting, Elizabeth started generating responses from very desperate recipients, some of whom were not compatible with her blood type or in her immediate geographical area. Discouraged, Elizabeth realized that she did not want to make the decision herself: she was worried that someone with a questionable lifestyle might receive her kidney.

I put a posting on Living Donors Online saying I was B type and looking for somebody in the Ottawa area...because I really didn't want to travel. I really didn't want to go out of the country, but I really didn't want to go to Toronto or BC. So, I put the posting up thinking that I'll find my own recipient. Maybe, I got three or four answers: a nice woman from Toronto, somebody from Ottawa, but they weren't even the right blood type. I wrote them back and said, 'I'm really sorry.' Either they weren't the blood type or we didn't want to go outside Ottawa. So then I took the

posting down because I thought I don't really want to do it this way and that's when I decided that I'm going to go to the hospital and I'm going to let them...it's not whose right is it. It's not my right to choose who to give this to...it should be a medical decision. It's not quite the same as related donation: if you're going to do anonymous, I really believe that it's not my right to choose who is a better choice, you know? Because, you know, they have better values or they're my background.

So, Elizabeth decided to let the Ottawa Hospital Renal Transplant Clinic make the decision for her. At first, Elizabeth was unsure about how to approach the Ottawa Hospital Renal Transplant Clinic with her desire to become a non-directed living organ donor, so she decided to contact Jenny Oad.

First, Jenny Oad advised Elizabeth to contact the Ottawa Hospital about the possibility of becoming a kidney donor. So, Elizabeth phoned the Ottawa Hospital, but the hospital never returned her call. Next, Jenny Oad helped her to draft an e-mail to send to a nephrologist at the Ottawa Hospital Renal Transplant Clinic. Elizabeth waited a couple of weeks for a response to her e-mail. Elizabeth sent the e-mail a second time and she still did not receive a response. At this point in our conversation, Elizabeth confessed that the Clinic probably had not believed that she was serious. Finally, Elizabeth contacted the Patient Relations Office for the Ottawa Hospital.

According to Elizabeth, the Patient Relations Office acts like an ombudsman for the Ottawa Hospital and Patient Relations staff spoke to the Ottawa Hospital Renal Transplant Clinic on her behalf, which enabled Elizabeth to speak directly with a transplant nephrologist. Elizabeth explained, "I got this call at work from (the transplant nephrologist), which really shocked me and we must have talked...it was quite a long time for me to talk to a doctor, but it was thirty to forty minutes. And he did a little

medical history... that was really encouraging.” Therefore, due to her persistence, Elizabeth successfully began the organ donation and transplantation process.

Once Elizabeth’s offer to donate a kidney was accepted, she had to undergo diagnostic testing similar to the testing that directed living organ donors are subjected to.

It was just a matter of me calling every few months just to remind them because I was never certain if they were just testing me...because that's what Living Donor Online makes clear is that they're really reticent about jumping in with non-directed donors...because they want to make sure that they really are committed and that it's not just a whim. So the first real sense that I got that this might happen was in September 2006 when (the living donor coordinator) called me up and introduced herself and said that, 'We are moving ahead now, but there is no guarantee, but I would like you to come in and let's go through your medical history.' Aside from the cursory one that (the transplant nephrologist) had done. So that was really, really exciting because that was the first time that I had been asked to come in...because I hadn't actually met anybody yet in a year and a half. So then I met (the living donor coordinator) and went through a very, very exhaustive checklist...probably the same one that you had to go through. So it's pretty exhaustive...and then, you know, all the 24-hour urine tests.

Elizabeth explained how she thought that the Ottawa Hospital was being especially cautious with their diagnostic tests because she was a non-directed living organ donor. In fact, Elizabeth, at one point, had to undergo a rather painful kidney biopsy when blood was found in her urine. Although she found the test uncomfortable, Elizabeth was determined because she felt that if she went through all of the testing that the Ottawa Hospital Renal Transplant Clinic would take her seriously. Eventually, Elizabeth became an active participant in her health care when one of her diagnostic tests showed that she had decreased kidney function. According to Elizabeth, she met the transplant nephrologist and they both agreed to conduct the test one more time and if the results were the same Elizabeth would no longer be considered a viable candidate for donation.

There was a little issue with my creatinine level. So when they did the renal scan my GFR was 83 and you know that you are going to lose kidney function when you lose one of your kidneys. In Canada, the cut off is around 80, but 83 is sort of marginal...so they were a little concerned and so was I. Because I am also an older donor, they said, 'Let's do it again.' I drank more water because I think that was maybe my problem. I tended not to drink enough water in general before my kidney donation...so it came back and it was 91.

The results of Elizabeth's second renal scan were more optimistic than her first scan and she was able to continue with the rest of the tests. Elizabeth's determination to donate prompted the Ottawa Hospital Renal Transplant Clinic to develop a new protocol for screening potential non-directed living organ donors. Elizabeth explained that this was one of her best experiences during the organ donation and transplantation process:

The best part of the process was feeling that I was able to make a difference, not just for the recipient, but for the hospital. It was that whole sense of being able to help in a small way because I don't take a lot of credit for any of this. Because the transplant team all had to be committed to it, to make it happen. I was just happy to be a part of that process.

Although Elizabeth confessed that she had been distressed by the fact that she had to be so persistent in order for the Ottawa Hospital Renal Transplant Clinic to take her offer to donate seriously, in a sense, her persistence made it more feasible for those interested in non-directed organ donation to donate a kidney.

Many living organ donors like Elizabeth, are able, through education and negotiation with the Ottawa Hospital Renal Transplant Clinic, to become active members of the health care process. However, when asked to describe the worst part of the organ donation and transplantation process, many directed and non-directed living organ donors identified their hospital experience to be the most unpleasant feature. Surgery and post-

transplant recovery take place in either the Ottawa General Hospital or the Ottawa Civic Hospital, which are both physically separate from the Ottawa Hospital Renal Transplant Clinic. The hospital is a hierarchical and bureaucratic environment where everyone from doctors, nurses and patients is expected to act in predictable ways with the patient taking on a passive role (Foucault 1977, 1989; Lupton 1997; Scheper-Hughes and Lock 1987). Therefore, the active donor body becomes a passive donor body during post-transplant recovery in the hospital. The passive role that donors are expected to adopt once they are recovering in the hospital is exemplified in Maggie's narrative regarding her post-operative recovery as a patient of the Ottawa Hospital.

Maggie:

Maggie was the very first non-directed living organ donor that I interviewed at the Ottawa Hospital Renal Transplant Clinic. Maggie, a government employee in her early 50's, had wanted to donate a kidney since she was a teenager. When Maggie was 17, her best friend's sister became very ill and was diagnosed with renal failure. Maggie's friend was tested along with the rest of her siblings in an attempt to find a potential donor. The only viable match was a brother who decided that he really did not want to donate a kidney. At that point, Maggie expressed a desire to be considered as a potential donor because, as she explained during our interview, she has O+ blood and thought that as a result she would make a good candidate.² However, at that time, the transplant team would only allow a biological relative to donate a kidney. Unfortunately, Maggie's best

² Among transplant nephrologists, people with O blood type are considered universal donors.

friend's sister died, but Maggie never gave up hope that one day she would fulfill her wish to become a kidney donor.

Although Maggie's narrative is largely positive, she is critical of the Ottawa Hospital Renal Transplant Clinic because of what she perceives as a lack of communication between the donor and the Clinic. Maggie explains that she was never made aware by the Ottawa Hospital Renal Transplant Clinic that the entire process was going to take two years to complete. Furthermore, Maggie explained during our interview that the worst part of the organ donation and transplantation process was her post-transplant recovery. Maggie has a very high pain tolerance and so she barely used the morphine pain pump that the Ottawa General Hospital tends to provide for both directed and non-directed living organ donors. Maggie found that she did not like how the morphine made her feel, so she decided not to use the pain pump, which had its consequences.

I'm not certain if they thought I was trying to put on a brave face and 'butching up.' I don't know what their reasoning was, but they needed to see that I was using the pump so many times an hour before I was released. And, I, in fact, had to do that. That to me is silliness and the reasoning behind it was: even though I was not consciously experiencing unmanageable pain the drug in my system would relax my body better to heal after surgery.

Therefore, in order to be released from the hospital, Maggie had to comply with her doctor's orders and use her morphine pain pump, even though she did not feel that she needed it.

Catherine:

Catherine donated a kidney to her sister who had been diagnosed with Polycystic Kidney Disease (PKD). I interviewed Catherine, along with her husband, only a week after she had donated to her sister. Unfortunately, at the time of our interview, Catherine's sister had been readmitted to hospital with mild signs of graft rejection. Catherine was pleased to be able to help her sister, but like most directed and non-directed living organ donors, Catherine did not enjoy her hospital stay.

The best part will be if (recipient) will be well and get some kind of normal life and not be so bound...The worst part was my hospital stay...I was in a very busy room and that was the part that I found the most frustrating...noisy at night...I mean there were people in pain and people that needed care and I understand the whole thing...I was relatively good...I didn't buzz the nurses unless I had to because they were busy and I didn't want to disturb them.

Conclusion:

The narratives discussed in this chapter, speak to how these donors became active participants in the medical encounter with the Ottawa Hospital Renal Transplant Clinic. Their active role is evident in their negotiation around diagnostic testing and dates for the surgery. Moreover, these suggest that by becoming an active participant in the medical encounter with the Clinic, donors construct the organ donation and transplantation process as a meaningful experience, which is focused on helping to save the life of a loved one, or even a stranger.

In contrast to the narratives of contemporary donors, Nola's narrative also illustrates the unique quality of her experience as the first living kidney donor in Canada. Her narrative shows how the positive doctor-patient relationship transcended the

boundary of the hospital prior to the routinization of the kidney donation and transplantation process in Canadian medical practice.

The narrative of Dr. Anderson suggests that health-care professionals at the Ottawa Hospital Renal Transplant Clinic understand how meaningful the organ donation transplantation process is for directed and non-directed living organ donors. In addition, what he refers to as the “grey zone” of transplantation, Dr. Anderson recognizes that it can be important for a donor to donate a kidney to a loved one, even if it means compromising their own health.

Finally, the donor narratives examined in this chapter reveal a generally negative encounter during post-operative recovery in the hospital. Gary, Carrie, Elizabeth, Maggie and Catherine went from being active participants in the transplant process at the Ottawa Hospital Renal Transplant Clinic, to becoming passive participants during surgery and recovery in the hospital.

Chapter III

Mediating and Negotiating Directed Living Organ Donation in the Family.

When I first began the organ donation and transplantation process in 2006, my mother, father and I all sat around a conference table at the Ottawa Hospital Renal Transplant Clinic as the recipient coordinator explained how the matching process works between potential donors and their recipients. The recipient coordinator explained that I might not be a suitable match for my mother and that her best chance would be to receive a kidney from a sibling. On a previous visit to the Ottawa Renal Transplant Clinic, my mother and I had met with the living organ donor coordinator who had been interested to learn that my mother came from a large family. However, the living organ donor coordinator cautioned my mother against asking her siblings to donate. Instead, the living organ donor coordinator provided my mother with her business card and instructed my mother to give the card to her siblings. My mother's eldest sister expressed an interest in donating, but she later discovered that she only had one fully functioning kidney. After I completed the organ donation and transplantation process, my mother's younger sister decided to get tested as a potential donor in case my mother ever needed another kidney.

The Ottawa Hospital Renal Transplant Clinic realizes that support from family is very important for directed and non-directed living organ donors throughout the organ donation and transplantation process (The Kidney Foundation of Canada 2005). Lisa, the living organ donor coordinator, encourages prospective directed and non-directed living organ donors to discuss their decision to donate a kidney with family members. Other studies of the organ donation and transplantation process have also highlighted the

involvement of family members. While conducting anthropological fieldwork on directed living organ donation at a prominent transplant centre in Pakistan, Moazam (2006) observed that family members were active partners in the organ donation and transplantation process. However, she concluded that family involvement could be coercive in nature, since young women were often pressured into donating a kidney to male relatives (Moazam 2006). Furthermore, Simmons' et al. (1977) sociological study on directed living organ donation determined that "black sheep" family members donate in an attempt to gain the approval of their relatives. As these examples show, family pressure can motivate directed living organ donors, making them feel obligated to donate a kidney to a loved one. The Ottawa Hospital Renal Transplant Clinic is vigilant in attempting to discover coercion among family members. However, directed donor narratives suggest that negotiation, mediation and manipulation does occur within families throughout the organ donation and transplantation process.

Directed living organ donor narratives reflect the fact that family members negotiate with one another over the eligibility of a prospective donor before contacting the Ottawa Hospital Renal Transplant Clinic. Moreover these narratives illustrate how family members mediate the organ donation and transplantation process. For instance, in many cases, siblings negotiate with one another when determining who will become the donor. Usually, the eldest sibling donates, while the younger ones are kept "in reserve" in case the recipient needs another transplant later in life. Furthermore, directed donor narratives suggest that these donors experience pressure from within themselves to donate. Finally, these narratives show that directed living organ donors manipulate the

social situation by enlisting the help of family members to try and convince a recipient to accept the offer of a kidney.

The first part of this chapter discusses how, in collaboration with the Ottawa Hospital Renal Transplant Clinic, family members decide who will be designated as a donor. The second part of this chapter explores how some directed living organ donors feel that it is their moral obligation to donate a kidney to a loved one. Finally, the chapter concludes with an exploration of how directed living organ donors, with the help of their extended families, attempt to convince recipients to accept the offer of a kidney.

Candice:

I interviewed Candice about her experience as a directed living organ donor in July of 2009. At the time of our interview, Candice and her eldest son were celebrating their three-year transplant anniversary and both were enjoying good health. When Candice and her son began the organ donation and transplantation process, it was Candice's husband who came forward as their son's potential kidney donor. However, both Candice and her youngest son also agreed to be tested. As she explained: "And, then, I got tested too, which was kind of...OK, we'll all get tested, but I really thought that my husband was going to be the donor and he ended up with a diagnosis of pre-diabetes." So, the Ottawa Hospital Renal Transplant Clinic eliminated Candice's husband as a potential donor. In this situation, Candice became the next logical choice. However, Candice's youngest son expressed an interest in donating. In turn, Candice and her husband discussed the strategy of keeping their youngest son in reserve in case his older brother needed another transplant: "My other son, of course, was quite interested...and I thought,

‘Well, that’s nice, but you’re young so why don’t you wait...in case the first one needs to be replaced in the future?’” Suddenly, Candice found herself as her son’s potential donor.

Although Candice wanted to donate a kidney to her son, she was afraid of experiencing pain associated with the transplant surgery. Candice explained that she had to mentally prepare herself for the organ donation and transplantation process because of her fear of pain: “But I’m a sucker and I hate pain (laughter). I don’t know if sucker is the right word, but I do hate pain.” So, the Ottawa Hospital Renal Transplant Clinic advised Candice to inform her transplant surgeon that she did not want to experience any pain during her post-transplant recovery. However Candice explained that she still had to mentally prepare herself for surgery:

So having to think about going through surgery and psyching myself up was one thing. The actual physician that I met with, who was going to do my surgery, he just said, ‘Just make sure that everybody knows that you don’t want to have any pain that you’re afraid of having pain.’ He said, ‘Just talk about it, spread the news around.’

When Candice began the organ donation and transplantation process, she was content with her husband’s decision to become the donor because he strongly expressed his desire to donate. However, when it became clear that Candice’s husband was no longer a viable donor, she had to overcome her fear of pain to donate. Furthermore, Candice and her husband prevented their younger son from becoming a potential donor because they wanted to keep him in reserve for his brother in case another transplant might be required. The idea of keeping a sibling in reserve is also present in Rick’s narrative about his experience donating a kidney to his wife.

Rick:

Rick was finally able to donate a kidney to his wife in February 2009, four years after being informed by the Ottawa Hospital Renal Transplant Clinic that he was no longer a viable donor. Rick's wife had been diagnosed with the genetic disorder, Polycystic Kidney Disease (PKD). Eventually, Rick's wife was transferred to the Ottawa Hospital Renal Transplant Clinic and they determined that her best chance of living a normal life was to receive a kidney transplant. So, family and friends presented themselves as potential donor candidates. However, Rick explained that he always felt that he should be the one to donate a kidney to his wife, since they were such a compatible couple. Unfortunately, Rick's wife suffered from an antibody issue, which according to Rick, caused her to reject all potential donors, including himself. Therefore, Rick's wife was placed on dialysis for a year, which allowed the couple and the Ottawa Hospital Renal Transplant Clinic to evaluate possible solutions.

Rick and his wife began reading about innovative transplant programs offered in both Canada and the United States. Eventually, Rick and his wife settled on the positive cross match program offered at the Toronto General Hospital. The Toronto General Hospital refers to the program as the HLA Desensitization Program (Toronto General Hospital 2009). According to Rick, the positive cross match program is a widely successful program that was introduced in 2005 at the Toronto General Hospital. Rick described what the positive cross match program attempts to accomplish: "They essentially neutralize the antibodies that (the recipient's) got that rejects my tissues. So they can make her compatible with me; they make her match me. That's essentially what

it comes down to.” Therefore, as soon as his wife was accepted into the positive cross match program, Rick was determined to become her kidney donor.

As part of the cross match program, Rick’s wife had to undergo treatment in order to eliminate the antibodies that were preventing her from accepting a donor kidney. Rick explains the process:

It requires a lot of treatments: plasmapheresis starting in September of 2009. She started those treatments. She started plasmapheresis and another treatment, which involves taking blood products from other people and introducing that into her system. Of those two treatments, in total, she probably had 10 or 12 treatments in the fall and up to January of 2009 to prepare for this.

The positive cross match program seemed to be going well, until Rick realized that he might not be able to donate to his wife. A few years before his wife started her treatments at the Toronto General Hospital, and when she was first being considered as a candidate for organ transplantation, Rick experienced a health crisis of his own after being diagnosed with prostate cancer. Fortunately, Rick’s cancer was treated successfully and he was soon declared cancer free. However, Rick worried that his former cancer diagnosis would eliminate him as a potential donor. So, he decided to enlist the help of his urologist to convince the Toronto General Hospital that he was healthy enough to donate. Finally, after convincing the Toronto General Hospital that he was healthy, Rick was able to successfully donate a kidney to his wife.

Around the time that Rick and his wife were going through the positive cross match program, Rick’s youngest daughter expressed an interest in donating a kidney to her mother. However, Rick’s eldest daughter had also been diagnosed with Polycystic

Kidney Disease (PKD) and Rick and his wife knew that one day his eldest daughter would need a transplant. Rick explained that:

The younger daughter, of course, she wanted to donate. That was really very emotional because there is the younger daughter who we really didn't want to donate... and in the back of our minds, we're thinking, our older daughter will need the younger daughter someday.

Rick and his wife respected their daughter's decision to donate and she continued through the testing, however, she was rejected as a potential donor. Rick does not know why his daughter was rejected as a potential donor and he suggests that the Toronto General Hospital shared their view that the eldest daughter would someday need a transplant from her younger sibling. Like Candice, Rick and his wife along with the Toronto General Hospital are keeping the younger sibling in reserve. Aside from keeping siblings in reserve, when siblings are called upon to donate, they negotiate amongst themselves in determining the best donor candidate. Usually, as illustrated in the following narratives from Shannon and Tom, the eldest sibling steps forward as the best possible donor candidate.

Shannon:

Shannon donated a kidney to her brother in February of 2009 and at the time of our interview, she was just getting back to work. Shannon is very active in sports and she enjoys playing hockey on a recreational team. Moreover, Shannon also plays the bagpipes and is a member of a local Highland band. Shannon comes from a small, but cohesive family consisting of a younger sister and brother. She recalled that she was shocked when her brother phoned her with the news that his kidneys were failing, especially since they do not have a family history of kidney disease. Eventually, the doctors surmised that her

brother's kidneys were too small to support his body and he was placed on dialysis. Next, the doctors informed Shannon's brother that he would need a transplant in a year's time.

Both Shannon and her sister considered donating to their brother. However, they agreed to wait and see how he responded to the dialysis treatments. Shannon and her sister decided to attend an information session on living organ donation offered by the Ottawa Hospital and held at the General Campus, while they waited to see how their brother's treatments were affecting his condition. Shannon explained that, "We didn't know who would be donating. We just wanted information because if the dialysis helped, we wouldn't have to go through the transplant." Eventually, Shannon's brother became sick while his kidney function continued to decline and the sisters had to determine who would be the one to donate.

Shannon explained that, initially, her younger sister was going to be the one to donate a kidney to their brother. However, after a visit to the family doctor, Shannon's sister was made aware of an underlying health condition that prevented her from donating a kidney. Therefore, Shannon quickly volunteered to become her brother's donor:

My sister's family doctor recommended that she not do it because she's got health issues... (Kim) and I called each other and all I said was, 'Do you want to donate or do you want me to donate? That's all I said to her and she says, 'Well, my doctor says that I really shouldn't. But if you can't, I will.' I said, 'Well, I'll just do it. I don't have any health issues.'

Shannon and her sister negotiated over who would go through the organ donation and transplantation process. Initially, Shannon's younger sister wanted to donate, but underlying health concerns prevented her from giving her brother a kidney and made Shannon the next logical choice.

Tom:

Tom, a long-time employee of the provincial government, lives in northern Ontario with his wife and children and he happily donated a kidney to his younger brother in May 2009. Tom explained that deciding to donate a kidney to his younger brother was the easiest decision that he has ever made.

As the oldest of three brothers, Tom felt that it was logical for him to be the one to donate to his younger brother, the middle one of the three men. Tom and his siblings had known about their brother's kidney failure for the past 10 years, so it was not a surprise when Tom received the call informing him that his brother was in need of a transplant.

After Tom and his brothers were tested, the Ottawa Hospital Renal Transplant Clinic determined that Tom and his youngest brother were both suitable matches to donate a kidney. However, Tom felt that by virtue of being the elder brother, he should be the one to donate: "I'm six or seven years older than my youngest brother, so the logic was I would donate, because he would then be available to donate if later on (the recipient) needed another one. It was logical...it was just logical." Therefore, as the eldest brother, Tom would donate first, while his youngest brother was kept in reserve. As Tom and Shannon's narratives suggest, directed living organ donors seem to, without much family pressure, want to donate a kidney to a loved one. However, unlike non-directed living organ donors, some directed living organ donors feel a different sense of moral obligation to donate a kidney. This type of moral obligation to donate a kidney seems to come from within the donor, independently of the influence of family members.

John:

I had the opportunity to interview John, at the Ottawa Hospital Renal Transplant Clinic, six months after he had donated a kidney to his father. John works investigating cases of fraud for one of the five major banks in Canada. John explained during our interview that his relationship with his extended family and his father, in particular, is strained.

John attributed his dysfunctional relationship with his father to their inability to relate to one another. John has known since he was a child that his father, diagnosed with Polycystic Kidney Disease (PKD), was quite sick. However, once it was firmly established by the Ottawa Hospital Renal Transplant Clinic that a kidney transplant was his father's best chance of survival, John and his siblings, excluding a sister who had also been diagnosed with Polycystic Kidney Disease (PKD), volunteered for testing.

To put it very bluntly, my father and I are not close. I don't particularly like the man and I'm not left with the impression that he's particularly fond of me. Be that as it may, this didn't come as a surprise. We've known that he was sick for a long time and when it became clear that his...that the only course of action for him was to receive a kidney from someone else. Everyone, but my sister submitted for testing...my sister is diagnosed with PKD as well.

When I asked John why he donated a kidney to his father, he replied that he donated out of a sense of moral obligation:

It was one of those questions that you have ask yourself: 'Can I live with myself if I say no? Not because it's my father, but because I hold the means of extending someone else's life. It is certainly reasonable to think that there is a list and those lists do get satisfied, but I'm left thinking that the reality of that is that a lot of people never get off the list. So, 'Can I live with myself' The answer was "No."

John spent a year undergoing various diagnostic tests, which he found particularly frustrating because he had to put his life on hold. Moreover, John's father suddenly decided that he did not want to go through with the transplant and the Ottawa Hospital Renal Transplant Clinic postponed John's testing. The living donor coordinator encouraged John to talk to his father about why the testing had stopped. John explained that school was his top priority but if his father wanted to continue with the transplant, John would be ready. Eventually, his father changed his mind and John was finally able to donate a kidney.

I asked John if his relationship with his father had changed since the transplant and John pragmatically replied that his relationship with his father was still strained and that he had donated knowing that their relationship would never change:

It's not really a subject of conversation. I ask him how he's feeling and he'll say good or bad or whatever he is that particular day, but it's not as though I look at him and see that he has something that belongs to me or even did belong to me. I suppose in that respect it's not totally different from the way that I sort of view giving blood. It's true, genetically it is yours and identifiable as such, but once it's gone, it's gone. Isn't that the premise of donation of any kind?

John decided to donate a kidney to his estranged father because of an internal sense of obligation. Moreover, John's narrative would suggest that he was not pressured by his family or by his father into donating a kidney, since he describes his relationship with his family as fractured. Furthermore, John went through the organ donation and transplantation process knowing that his relationship with his father would not improve. A sense of moral obligation to donate a kidney to a loved one is also present in Flora's narrative about her experiences donating a kidney to her husband.

Flora:

Flora is a retired elementary school teacher who donated a kidney to her husband three years prior to my research. Like John, Flora felt a strong sense of moral obligation to donate a kidney to her husband. Flora, a devoted grandmother and active member of the United Church, has been happily married to her current husband for more than 33 years. Flora's husband, also a retired teacher, had been diagnosed with kidney disease 10 years earlier and eventually both Flora and her husband knew that he would have to go on dialysis, or receive a kidney transplant. Flora explained that:

He was always open to be on dialysis. The children had said that they would donate their organ; they would give him a kidney when the time came. He didn't want to put the children through this. He thought that they were young and he didn't want to put them through this and he knew he was going to be on home dialysis and he was going to do this for a couple of years. Then, the waiting time for a donor in Ottawa was 4 to 6 years and he felt that that was a bit steep. My blood group, I am an O+... and I said that is a good start and I'll get tested and we'll just see.

Flora ended up being a good match to her husband and they both began the organ donation and transplantation process. However, Flora confides that, at first, she was not too sure that she wanted to donate. Flora explained that she felt that she had a moral obligation to donate a kidney to her husband, although he did not pressure her to donate.

At one point I felt that I had to do it because how could I live with myself and live with him after if I refused. I kept that inside; I kept that to myself. I felt pressured in a way, but pressure from myself. I was never afraid; I trusted the hospital and I trusted everyone completely that they would not do this if there could be damage to me. I trusted that they would take care of me and I knew that he would be so much better.

Therefore, like John, Flora felt a moral obligation to donate to her husband because she felt that she had the means by which to extend his life. The donor body is not only the

site of social mediation and manipulation by family members, but also by the donor themselves through an internal sense of obligation towards the recipient.

Throughout the organ donation and transplantation process, directed living organ donors usually seek the support of their family members. However, the living organ donor coordinator's narrative suggests that some family members attempt to prevent a loved one from donating an organ.

Living Organ Donor Coordinator:

Lisa has been the living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic since 2006. However, at the time of our interview, Lisa was considering taking a year off work to be with her father in Japan. As living organ donor coordinator, Lisa is the first person that a potential living organ donor will contact about the organ donation and transplantation process. Lisa provides potential donors with information so that they can make a fully informed decision and she also provides emotional support for the donor. While I was going through the organ donation and transplantation process, Lisa would frequently call to find out how I was doing emotionally.

Along with providing directed and non-directed living organ donors with information, scheduling their diagnostic tests and providing emotional support, Lisa encourages potential donors to speak with their family members regarding the organ donation and transplantation process. Lisa recognizes that family support throughout the organ donation and transplantation process is very important for directed living organ donors. However, family members can also attempt to manipulate loved ones in order to dissuade them from donating a kidney. For instance, a woman interested in donating a

kidney to her friend contacted Lisa in order to find information about the organ donation and transplantation process. In turn, the woman's husband found out that his wife wanted to donate a kidney and came to the Ottawa Hospital Renal Transplant Clinic to speak with Lisa regarding his wife's decision to donate. According to Lisa, the woman's husband was quite adamant that his wife would not be donating a kidney:

Support from family, I think, in a fairly significant way...we've had at least two to three cases that I can think of off the top of my head where an individual wanted to donate to an acquaintance...so not somebody that they knew intimately, but like a breakfast buddy, for instance...and their spouse was not supportive, their spouse actually came and spoke to me to try and get more information about it and ultimately, at the end of the conversation, he said, 'My wife will not be donating.'

The lack of support from family can impact the decision of a potential donor about whether to continue with the organ donation and transplantation process. However, the narratives of directed donors like Hope suggest that some donors will –perhaps strategically—neglect to inform certain family members about their decision to donate.

Hope:

Hope decided to donate a kidney to a childhood friend and was supported in her decision to donate by her husband, sister and her recipient's family. However, Hope decided to wait until after donating a kidney before telling her parents.

As a child, Hope was raised in a traditional Italian Catholic family and she enjoyed playing with the neighbourhood kids. Eventually, years later, Hope learned from her parents that one of her old childhood friends, Marco, was in need of a kidney transplant. Hope recalled that as a young boy, Marco was always smiling and had a sense of humour. She explained that her parents are close friends with Marco's parents, because

they both come from the same region in Italy. One day, Hope received a phone call from her mother who told her that Marco, who had been diagnosed with diabetes, was waiting for a kidney transplant. Hope explained that throughout the entire conversation, she really absorbed what her mother was saying. Afterwards, Hope went out to her garden to think about the conversation that had transpired with her mother.

While working in her garden, it took Hope only 10 minutes to decided that she wanted to donate a kidney to Marco. Hope went inside the house to find her husband and discuss her decision with him. Initially, Hope explained that her husband was supportive of her decision to donate. He cautioned her to take a couple of days to think it over and if she still felt the desire to donate, he would still support her decision. After considering her decision for a couple of days, Hope decided that she really wanted to donate a kidney.

Initially, Hope phoned Marco's brother to get more information about the organ donation and transplantation process. Hope explained that Marco's brother was quite surprised and pleased to discover that she wanted to donate, so he provided her with the contact information for Lisa, the living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic. In turn, Hope contacted Lisa in order to start the organ donation and transplantation process.

Once Hope started the process of becoming a directed living organ donor, she informed her sister and Marco and his family. However, Hope explained that she decided to withhold her decision from her parents because she didn't want them to worry. In fact, Hope decided not to tell her parents for another year and only after she had completed the

transplant. “So, I thought that I have known this for a year and I haven’t told my mom and dad.”

Hope found that keeping her decision about donating from her parents very difficult and that there were a few occasions where she almost told them the truth. On one such occasion, Hope’s parents attended a Kidney Foundation function with Marco’s parents. At the function, Marco went to speak with her parents: “So, he went up to my mom and dad and said, ‘I found a donor!’” Hope explained that her parents were happy to find out that Marco had found a potential donor, but that they had no idea that it was their own daughter. Eventually, once Hope completed the transplant and was discharged from the Ottawa General Hospital, she had to tell her parents about the transplant.

Immediately after Hope left the hospital, she phoned her sister and asked her sister to meet her at their parents’ house. So, with the support of her sister, Hope finally told her parents about the transplant.

I started to cry, just thinking about it. I said, ‘Sit down, I have something to tell you and it’s really important.’ I said, ‘Ma, last Thursday, I got operated on.’ And she lost it! I said, ‘Ma come back here!’ I hadn’t even told her what for yet. I said, ‘It’s all good, it’s all good.’ So, I sat down and I said, ‘I gave Marco a kidney last Thursday.’ And they both started to cry.

Hope explains that after she told her parents about the transplant they both overreacted, thinking that she was going to die. However, Hope’s parents eventually supported their daughter in her decision to donate. Therefore, by intentionally withholding information about her decision to donate, Hope avoided her parents’ attempts to prevent her from donating.

Sometimes, directed living organ donors not only have to convince their family members of their decision to donate an organ, they also have to try and convince their recipients to accept the offer of a kidney. Some directed donors, like Fred, decide to go through the testing before informing their potential recipient of their decision to donate in case the potential recipient tries to prevent them from going through the testing. Convincing a recipient to accept a kidney tends to work well when the donor recruits the recipient's family to help.

Fred:

I interviewed Fred, at the Ottawa Hospital Renal Transplant Clinic in June of 2009, only five months after he had successfully donated a kidney to his brother-in-law. Fred is a federal government employee who enjoys drag racing in his spare time. Fred's brother-in-law is diabetic and while on vacation in June of 2008, he lost his vision in one eye. Upon returning home, Fred's brother-in-law was admitted to the hospital, where Fred would visit to give him moral support.

Fred explained that it did not take him long to decide that he wanted to donate a kidney. So, he contacted the living donor coordinator at the Ottawa Hospital Renal Transplant Clinic in order to get information on the organ donation and transplantation process. Moreover, Fred began to read everything that he could find on living organ donation before eventually deciding to come forward as his brother-in-law's potential donor:

I contacted Lisa (the living donor coordinator) in June and she sent me all the information. So, I read all the pamphlets and brochures that they gave me: went on a few different websites to find out what was involved in the

procedure. I just wanted to have enough information, because knowing my brother-in-law he would have said, 'No.'

Although Fred kept his decision to donate from his brother-in-law, he did tell the rest of his family. Eventually, Fred needed the support of his extended family in order to try and convince his brother-in-law to go through with the transplant. Fred explained that he and his extended family got together with his brother-in-law to convince him to have the transplant.

So, we invited them back to the house because it was at that point that I thought that I am going to tell them. So, we sat down and his wife had told him in the car on the way over what was happening and I had enough information that he really couldn't say no to it because I had a counter for everything that he was going to say. His oldest son had offered to do it, but he didn't want to involve him because diabetes runs in the family. I said that I read everything and looked up everything. So, we asked for 24 hours and 24 hours later, he said, 'We will go through with it.'

Fred knew that there was a chance that his brother-in-law would refuse the offer of the kidney. So, Fred with the help of his extended family convinced the brother-in-law to go through with the transplant. The donor body is the site of family mediation and manipulation in determining which family members will donate to the recipient. Furthermore, directed living organ donors can also manipulate recipients into accepting their offer of a kidney by enlisting the help of extended family and even the Ottawa Hospital Renal Transplant Clinic, which ultimately determines the suitability of donors.

Conclusion:

Lisa, the living organ donor suggests that support from family is crucial for directed and non-directed living organ donors throughout the organ donation and

transplantation process. The narratives analyzed in this chapter illustrate how living organ donation is negotiated within the family and how family members determine who will get to become the donor. As Candice, Rick and Tom's narratives suggest, children and siblings can be kept in reserve in case the recipient might be in need of another transplant later in life.

The narratives of John and Flora show how potential donors can experience pressure from within themselves to donate a kidney to a loved one. A study conducted by Kaufman et al. on organ donation and transplantation among the elderly concluded that “[t]he possibility of giving away a part of the body becomes implicated both in the demonstration of care and love and in the ability and responsibility to prolong another life” (2006: 83). Similarly, both John and Flora felt that they had the means by which to extend the life of a loved one and that they could not refuse to donate. In a sense, the donor's body becomes the site of a moral struggle with the self over whether to donate a kidney to a loved one.

Hope's narrative illustrates how a donor can strategically withhold information from relatives who might react negatively to the donor's decision to donate a kidney. Hope decided to avoid telling her parents of her wish to donate a kidney to Marco until after she had undergone the donation process. Finally, Fred's narrative illustrates how a directed living organ donor can manipulate a recipient into accepting the offer of a kidney. Interestingly, in her anthropological study about why recipients refuse the offer of a kidney, Elisa J. Gordon concludes that “[a]lthough patients expressed the view that living donors have an extra kidney to spare, they were reluctant to accept it because of

fear of harming the donor” (2001:251). Fred, aware that his brother-in-law might refuse the offer of his kidney decided to enlist the help of his extended family to try and convince his brother-in-law to accept the offer of a kidney. As the narratives considered in this chapter suggest, a donor’s extended family can provide emotional support during the organ donation and transplantation process, can attempt to prevent a loved one from donating, and can socially manipulate the recipient into accepting the offer of a kidney.

Chapter IV

Kidney Shaped Box: Gifting and Reciprocity in Directed Living Organ Donation.

As I lay on the surgical table waiting to donate my kidney, the transplant team tried to keep me at ease by making small talk. One of the scrub nurses jokingly asked if I wanted the kidney gift-wrapped since I was donating so close to Christmas.

Arlene Macdonald writes that “[t]he metaphor that heralds donation or receipt of an organ as conferring or receiving ‘the gift of life’ is circulating in myriad official and unofficial transplant discourses and is omnipresent in the public and private narratives of donors, recipients and transplant professionals” (2009: 9). The dominant clinical narrative at the Ottawa Hospital Renal Transplant Clinic refers to the donated kidney and organ donation as an altruistic “gift of life.” Similarly, the literature that the Ottawa Hospital Renal Transplant Clinic provides to potential directed and non-directed living organ donors refers to the donated kidney as a “selfless gift” (The Kidney Foundation of Canada 2005: 17). By referring to the kidney and the donation experience as altruistic gifting or the “gift of life,” the Ottawa Hospital Renal Transplant Clinic ensures that the kidney and the body of the directed and non-directed living organ donor does not become commodified within a market economy (Fox and Swazey 1974, 1992; Sharp 1995, 2006; Scheper-Hughes 2007). Moreover, giving the “gift of life,” encourages directed and non-directed living organ donors to give up ownership over the donated kidney, which ensures that a tyrannical relationship does not form between the directed living donor and the recipient (Fox and Swazey 1974, 1992; Sharp 1995, 2006; Scheper-Hughes 2007). A

tyrannical relationship occurs when the recipient realizes that they can never repay the donor for the gift of a kidney, which causes strain in the relationship between the donor and the recipient (Fox and Swazey 1974, 1992). However, the Ottawa Hospital Renal Transplant Clinic attempts to control the social context in which this form of gifting occurs between the donor and recipient. As I discuss later in this chapter, because the gift of a kidney is not completely selfless, the Clinic's attempts to control gifting and reciprocity are only partly successful. The gift of a kidney reinforces existing social ties between the donor and the recipient and also encourages reciprocation for the gift that has been given. Marcel Mauss argues that the nature of the gift is reciprocal and that "one gives away what is in reality a part of one's nature and substance"(1967: 10). Following this theoretical framework, the first part of this chapter focuses on the symbolic significance of the donated kidney for the directed and non-directed living organ donor. I argue that the donated kidney is not a selfless or altruistic "gift of life," since it is perceived as an extension of the directed living organ donor's self (Sharp 1995, 2006). The second part of this chapter discusses how the act of giving a kidney promotes a reciprocal response from the recipient towards the donor. I argue that the Ottawa Hospital Renal Transplant Clinic attempts to control the reciprocal nature of gifting through the living organ donor gala and the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) system of compensation.

Owning the Kidney:

As part of the Ottawa Hospital Renal Transplant Clinic's directed and non-directed living organ donor evaluation process, potential kidney donors have to meet with

a transplant social worker and a transplant psychologist. Potential living organ donors meet with the transplant social worker and the transplant psychologist separately. The main role of the transplant social worker and the transplant psychologist is to determine if the potential donor is being coerced into donating a kidney to the recipient. Moreover, the transplant social worker and the transplant psychologist are also concerned to ensure that the potential donor gives up ownership over the donated kidney upon completion of the organ donation and transplantation process, in order to prevent what medical sociologists Fox and Swazey (1974, 1992) call a “tyrannical relationship” from forming between the donor and the recipient. Many of the living directed and non-directed organ donors that participated in this study claimed that they no longer felt that the donated organ belonged to them and that they had given up ownership of the donated kidney. However, a few directed living organ donors admitted that they felt conflicted about whether the donated kidney still belonged to them, since it had come from their body and they still felt an emotional connection to the kidney. The following narratives depict how difficult it is for directed living organ donors to give up ownership over the donated kidney upon completion of the organ donation and transplantation process.

I asked Catherine during our interview whether she felt that the donated kidney still belonged to her or belonged to her sister:

I've been trying to put into my mind: 'OK, this is a gift that you have given and it's no longer yours.' So, whether I do have ownership or not, I don't really feel like I do, but, maybe I do? I've tried to make an effort since that point because it was something new that I hadn't thought of. I don't know. I guess I maybe took it that way.

After my interview with Catherine, I was left wondering about my own evaluation by the transplant social worker and the transplant psychologist. I recalled my meeting with the transplant social worker when she asked the question: Does the kidney belong to you or to your mother? I carefully pondered my response and weighed my options: I felt that if I said that the kidney still belonged to me, I risked being screened out as a potential donor. However, if I said that the kidney no longer belonged to me but to my mother, I felt that I would have a better chance of moving forward as a donor. So, I told the transplant social worker that once the kidney left my body and was transplanted into my mother's body that it no longer belonged to me and that I would not interfere in her lifestyle choices post-transplant. The transplant social worker seemed satisfied with my response, but as I left her office, I couldn't help but wonder if I had been entirely truthful. As my own experience suggests, it is not an easy matter to give up ownership of part of one's body.

Another directed living organ donor who still felt a strong connection to her donated kidney was Flora. I asked Flora how she refers to her donated kidney, specifically, whether she still calls it "her kidney." Flora responded that both she and her husband still refer to the kidney as being "her kidney."

This type of connection with the donated kidney tended to be stronger for those donors, like Flora, who lived with their recipients, and donors who had regular and frequent contact with their recipients. However, the non-directed living organ donors seemed to feel more of a connection with the kidney that remained in their body rather

than with the kidney that they had donated. For instance, Elizabeth, a non-directed donor thinks only about her remaining kidney.

I think about my own remaining kidney. I don't know if you do? But when I'm drinking water or something, I think: Oh, little kidney, I'm giving you water...I sort of personify my remaining kidney, but I don't relate to the kidney that is gone, although I think about it occasionally. I think about how it is doing. And I hope that it is being—again it comes down to the benefit of not knowing who your recipient is that you don't know if they are misusing it. Because, I've read a lot of stories on Living Donors Online where donors are really frustrated because they gave it to a brother and the brother is out drinking again and abusing their body and they're disappointed because they still feel a bit of ownership of that kidney.

This situation that Elizabeth describes is quite common in the sociological and anthropological literature on living organ donation. However, Elizabeth's statement confirms how conflicted directed living donors are about whether or not the donated organ still belongs to them once the organ donation and transplantation process has been completed.

However, not all of the directed living organ donors that I interviewed felt that the donated kidney still belonged to them. Candice, who donated a kidney to her son, felt that the kidney was a gift.

But once I had decided to give the actual kidney, it was like: 'OK this is going to be a gift.' And I remember speaking with the psychiatrist about that and that was one of the questions and I don't know how she worded it, but that was my thoughts at the time. It is a gift and it's something that is for my son and for any recipient. You would do it for somebody.

During our interview, I realized that I shared Candice's view regarding the kidney as a gift. However, I wondered about what type of gift a donated kidney really is, since most of the directed and non-directed living organ donor participants referred to the donated kidney simply as a gift and not as the "gift of life."

The Gift of Life or Just a Gift?

While the Ottawa Hospital Renal Transplant Clinic refers to kidney and organ donation and transplantation as “the gift of life,” the narratives of living directed organ donors tend to refer to the donated organ as being “just a gift” or a gift to mark a special occasion such as an anniversary or Christmas. The giving of gifts at Christmas and anniversaries helps to reinforce and maintain social relationships as these gifts are commonly reciprocated (Visser 2008). Significantly, it is not unusual for recipients of cadaveric organs to celebrate the anniversary of their transplant, commonly referred to as celebrating a “rebirthday,” and for family members of deceased organ donors to remember their loved one on the anniversary of their death and donation of their organs, especially when the deceased was a child, through scrapbooking and quilting (Sharp 1995, 2006). Like recipients of cadaveric organs, directed living organ donors and their recipients will celebrate the anniversary of the transplant through the exchange of gifts or commemorate the transplant event through scrapbooking. By calling the transplanted organ the “gift of life,” the Ottawa Hospital Renal Transplant Clinic constructs the gift of a kidney as a special category of gift, which cannot be reciprocated by the recipient.

By definition, it is only in special circumstances that one can “give life” to another person. Pregnancy and childbirth is the paradigmatic example of “giving life,” and it is commonly assumed, at least in Western culture, that children owe more than can ever be repaid to their parents, especially their mother. Similarly, in line with the broader North American medical discourse on organ donation, the Ottawa Hospital Renal Transplant Clinic constructs kidney donation as a gift which cannot be reciprocated. However, it

seems that directed living organ donors refer to the donated kidney as a gift that can be reciprocated and acknowledged by the recipient. For example, when Flora donated a kidney to her husband, it was a month before Christmas and she was left wondering what gift to get him for Christmas. Finally, since her husband had been advised to wear a pad over his new kidney in order to protect it while travelling in the car, Flora decided to make him a pillow that would cushion the kidney on long trips.

The first Christmas, he had to wear a pad and I told him to wear a pad in the car. I thought: 'What do I give him for Christmas now that I have just given him a kidney? I'll make him a pillow.' So, I searched for the right leather—kidney-coloured leather to make him a kidney shaped pillow. I made quite a few to get the right shape—to make it so it looked like a kidney. It's kidney-coloured red. I put it in a pretty box and gave it to him for Christmas.

For Flora, the kidney pillow that she made for her husband is a representation of her donated kidney and serves as a visual reminder for him of the gift that he has received from her.

Like Flora, Claude decided to donate a kidney to his spouse, but he wanted the kidney to be a surprise anniversary gift. However, Claude explained during our interview that because of a cancellation, the timing of the surgery did not coincide with their anniversary.

So, it didn't work out. I forget what it was. It was canceled, I think, three times. I said, 'OK, I'll make it your birthday present' and that didn't work out. I said, 'Well, maybe it's your Christmas present' and that didn't work out. So, by the time that we got it done—March 6th, I think, it was, yeah.

Every year, Candice and her son celebrate their transplant anniversary. Candice explained that the first year they marked the occasion by having a potluck dinner with friends and family in order to thank them for their ongoing support. The second year of

the transplant, Candice and her son went out for a beer and she gave him a decorative spray of twigs, while he gave her a card. Finally, the third year of the transplant, Candice and her son acknowledged the date with a phone call and a card, but they did not get together to celebrate.

Another way in which Candice commemorates her experience as a kidney donor is through scrapbooking. Candice brought her scrapbook to the interview and asked if I would like to see a picture of her kidney. However, Candice has learned through her experiences with friends and family that not everyone wants to see a picture of a real kidney, so she keeps the picture in her scrapbook cleverly hidden underneath a picture of a gift box. For Candice, having the transplant team take a picture of the kidney, helped her come to terms with the idea that her kidney no longer belonged to her:

Getting back to picture taking, I was curious to see what it looked like. I have a natural curiosity, but in my nursing career, I didn't get in to do the cadavers, so the only kidneys that I've seen are in the animal dissections that I did. So, I was curious to see...and they did it in context: they had the scissors on the table and that kind of thing...and you always know what size you're looking for, but then you go: 'Look at that.'

The narratives of Flora, Claude and Candice suggest that these directed donors conceive of the donated kidney not as the “gift of life,” but as the type of gift that is reciprocal, such as birthday, Christmas or anniversary gifts.

Candice commemorated her experience of organ donation and transplantation through scrapbooking, and the picture of her kidney is placed underneath a picture of a gift box in her scrapbook. Having a picture taken of her kidney outside of her body helped Candice to disassociate herself from the kidney. However, not all directed living

organ donors disassociate themselves from the donated kidney and even Candice continues to identify with the kidney that she donated to her son.

The Kidney As an Extension of the Donor’s Self:

As with recipients of cadaveric organs, directed living organ donors personify the donated kidney and as such, the kidney becomes an extension of the directed donor’s self (Sharp 1995, 2006). However, the Ottawa Hospital Renal Transplant Clinic discourages directed living organ donors from psychologically identifying themselves with the kidney by promoting the kidney as a “gift of life.” Nonetheless, directed living organ donors identify with the donated kidney through naming, gendering and imbuing the kidney with personality traits. In this respect, donors who have externalized an organ from their body through donation behave like the recipients of cadaveric organs, who have received an organ into their body from the outside. In both cases, the organ is personalized as a result of being separated from the “self” in which it was originally embodied.

One of the most common ways in which directed living organ donors seem to identify with the kidney is through naming. For directed living organ donors, the naming of the kidney can be significant for both the donor and the recipient as it reflects a shared experience. For instance, Rick and his wife decided to name the kidney, Buddy 3, in honour of his wife’s first two dialysis machines:

We joke around a little bit. We sometimes call it Buddy 3 because we called her first dialysis machine...she was on peritoneal dialysis at home and the first machine that we had we called Buddy 1. The second machine was called Buddy 2 because they gave us a new machine. And, so, we sometimes we call it Buddy 3. We kid around about it.

Like Rick, Fred and his recipient decided to name the kidney, however, they also decided to enlist the help of their extended family and Facebook to choose a name:

We even had a name contest. My sister-in-law, she kept a diary on Facebook and she started from the day that we went in until Chris (recipient) was up and around. I think it was three months after the operation that she kept it going. It's kind of neat, but they had a naming contest. What do you want to call it? We came up with everything from Billy the Kidney (laughter). I said Fred because I like Fred.

However, not all directed living organ donors are involved in the naming process. Tom, who donated a kidney to his younger brother, was somewhat surprised when he found out that his brother had named the kidney: “He refers to it as the bean (laughter). I think that he actually named it.”

Directed living organ donors also identify with the kidney through gendering. Interestingly, the gendering of donated kidneys has also been documented among recipients of cadaveric organs. For example a male recipient speculated that he might start to pee sitting down, because he had received a kidney from a woman (Sharp 1995, 2006). The gender of the kidney tends to reflect the gender of the donor rather than the recipient. One of the participants in my study, Jackie, donated a kidney to her husband who was diagnosed with the genetic disorder, Polycystic Kidney Disease (PKD). During our interview, Jackie gave a rather conflicted statement, claiming that the kidney no longer belonged to her, but that her husband had *her* kidney inside of him. Moreover, Jackie explained that she teases her husband about the kidney by telling him that he is now part woman. “Well, I guess it’s my kidney that he’s got...he’s part woman now (laughter).” Therefore, Jackie explains not only will her husband become more feminine but he will also begin to suffer from hot flashes since the kidney is menopausal.

Along with naming and gendering, directed living organ donors seem to imbue the organ with personality traits, which are reflective of the donor's personality rather than that of the recipient. Some of the most interesting personality traits given to kidneys are food cravings that are manifested by the recipient post-transplant. Although bizarre food cravings seem to manifest among recipients of cadaveric organs (Sharp 2006), there is at least one donor narrative that suggests recipients of live donor kidneys also experience bizarre post-transplant food cravings.

Drake, who donated a kidney to his wife, explains that she began to experience unusual food cravings after receiving the kidney. Drake took notice of his wife's eating habits when she began to crave foods that she normally would not eat. In fact, according to Drake, his wife began to crave foods that he had always enjoyed. "Interestingly enough, I am addicted to chips, pizza and hot sauce and my wife likes pizza, but she didn't like chips and she didn't like hot sauce. She had cravings (for these foods) afterwards." However, some donors, like Tom, do not take food cravings very seriously. Tom joked with his brother about what type of beer the kidney will like post-transplant: "I told my brother that he was going to start to get cravings for domestic beer and he hasn't. He said that the kidney has switched over to imported beer (laughter)."

Food cravings are not the only traits that directed living organ donors project onto the donated kidney. For instance, Amy and Candice personified the kidneys they donated with a set of moral guidelines. Amy decided to donate a kidney to a good friend whom she had known for 20 years. Amy explained during our interview that she had been raised a Roman Catholic and that she was still actively involved in her faith. However,

when Amy told her Catholic father that she was donating a kidney he responded by laughing and asking if her recipient was a Catholic. Amy replied that her recipient was not Catholic, but an Anglican. Amy's father responded: "That's good, she'll have a good, little Catholic kidney." Amy laughed and explained how she jokes around with her recipient about having a "good, little Catholic kidney."

Similarly, Candice jokingly told her son that the kidney she gave him was a monogamous kidney and that he would have to limit the number of girlfriends that he would have post-transplant. According to Candice, her son thought that her request was comical and began telling his friends that his donated kidney carried a purity clause.

I said that: 'It's a very safe practice,' and he looks at me and says, 'Are you serious?' And I said: 'Well, of course not, but you want to protect what's there.' He took that and ran with it that he has to remain pure (laughter). He tells all his friends that.

Candice uses the purity clause as a way of telling her son that he has to be careful with her kidney.

Finally, directed donors often feel that the kidney is an extension of themselves and that although they may have given up physical ownership of the kidney, they still feel an emotional connection. Sometimes this connection manifests in unusual ways such as the gendering of the organ, food cravings, or imbuing the kidney with personality traits. However, there are directed donors, like Flora and Candice, who believe that perhaps there will continue to be an almost mystical connection between themselves and the donated kidney. At first, Flora would brush up against her husband in the area where he had been operated to see if the kidney jumped or moved in recognition of her presence. When the organ didn't respond, Flora felt slightly disappointed. In a related manner,

Candice thought that her presence in the kidney had influenced her son when she phoned him and found out that they were both painting—Candice was painting the interior of her house. While her son believed that it was simply a coincidence, Candice thought that it could be something more and that they were somehow connected through the shared organ. Moreover, each of these narratives reflects the fact that the gift of a kidney, similar to a Christmas or anniversary gift, maintains the substance or spirit of the person giving the gift (Mauss 1967). Furthermore, the gift of a kidney, like giving a Christmas or anniversary gift, reaffirms social relationships and is reciprocal (Visser 2008). The next section discusses the reciprocal nature of gifting and how the Ottawa Hospital Renal Transplant Clinic attempts to control the reciprocal nature of kidney donation, which I argue can actually lead to what Fox and Swazey (1974, 1992) refer to as the tyranny of the gift.

Reciprocity of the Gift Within The Transplant Clinic:

By referring to the kidney as an altruistic, “gift of life,” the Ottawa Hospital Renal Transplant Clinic constructs the donated organ as a special category of gift, which cannot be reciprocated. This lack of reciprocity could indirectly lead to resentment between the donor and the recipient (Fox and Swazey 1974, 1992; Simmons et al. 1977). Moreover, Mauss (1967) argues that an altruistic gift eventually becomes dangerous because the recipient can never give back a gift of equal value. However, the Ottawa Hospital Renal Transplant Clinic provides formal recognition of the contributions that donors make in giving the “gift of life,” through organizing the living organ donor gala and by promoting the Program for Reimbursing Expenses of Living Organ Donors (PRELOD). As such, the

Ottawa Hospital Renal Transplant Clinic indirectly acknowledges the reciprocal nature of giving the “gift of life” as the Clinic attempts to direct reciprocity into these “official” channels, and avoid spontaneous reciprocity from occurring between the donor and recipient.

The living organ donor gala is held every two years by the Ottawa Hospital Renal Transplant Clinic as a way of recognizing the contributions made by directed and non-directed living organ donors to organ donation and transplantation. I attended the living organ donor gala in October of 2008 at the Ottawa Hospital’s Civic Campus. Not only donors, but friends and family members of directed and non-directed living organ donors are encouraged by the Ottawa Hospital Renal Transplant Clinic to attend the gathering. The highlight of the living organ donor gala occurs when directed and non-directed living organ donors, in recognition for giving the “gift of life,” are presented with a medal. The front of each medal contains the inscription, “gift of life,” while the back contains the donor’s name, year of the transplant and the inscription, “in recognition.”

Accompanying the medal presentation is a series of speeches made by members of the transplant team, a representative from the Trillium Gift of Life Foundation and recipients. However, just as Sharp (1995, 2006) observes that public events commemorating organ donation do not include the narratives of the family members of deceased donors; the same is true for living organ donation. The donors themselves are not invited to share their stories with the audience. Instead, the Ottawa Hospital Renal Transplant Clinic relies upon recipients to recount a largely positive experience with the organ donation and transplantation process.

In 2008, the speech by the Trillium Foundation representative was also very positive, but also reflected ambivalence about reciprocity in organ donation. In his presentation, the Trillium representative explained how delighted he was to sign the cheques for those directed and non-directed living organ donors eligible for the Program for Reimbursing Expenses of Living Organ Donor (PRELOD). Suddenly, the Trillium representative stopped midway through his presentation. Apparently, he felt that his prior statement made it seem like the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) paid donors for their kidneys. He quickly explained that the purpose of the program was to help donors with expenses incurred during the organ donation and transplantation process and that payment for a kidney was illegal. Therefore, the Ottawa Hospital Renal Transplant Clinic, through the living organ donor gala and the Program for Reimbursing Expenses of Living Organ Donors (PRELOD), attempts to recognize, but not reciprocate for, the contributions that directed and non-directed living organ donors make to organ transplantation by giving the “gift of life.”

The Clinical Narrative and the Program for Reimbursing Expenses of Living Organ Donors (PRELOD):

The Ministry of Health and Long Term Care established the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) in order to increase organ donation rates in Ontario (Prasad 2008). The program is run by the Trillium Gift of Life Network and reimburses directed and non-directed living organ donors for expenses incurred during the organ donation and transplantation process, such as travel costs and the loss of income (Trillium Gift of Life Network Act 2006). Moreover, the program covers the expenses of those donors who live out of province, but who are donating in

Ontario (Prasad 2008). However, donor reimbursement is capped at \$5,500, which might not completely cover the travel expenses of donors coming to donate from outside of Ontario. The cap of \$5,500 concerned Dr. Anderson and was a topic of discussion during our interview.

When I met with Dr. Anderson, we discussed the potential financial barriers that directed and non-directed living organ donors face throughout the organ donation and transplantation process, which Dr. Anderson believes these barriers can be a deterrent to potential organ donors. He explains:

Many people have to take time off of work. Many people have to travel to the appointments. There may be certain tests that they are required to pay for if they are not insured. There is time off of work; there is time post-operatively, six weeks. The Ontario Government has a system of partial compensation for kidney donation and organ donation...it's called PRELOD. I think that it provides up to 5,500 dollars, or something like that to cover these expenses, but that may not be enough. Really, when you think about the time: lost wages related to work and sometimes travel. Sometimes potential donors may have to come from far, they may have to come from other countries, in fact. These costs don't necessarily get covered.

Dr. Anderson's concerns regarding the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) were also present in Tom's narrative about applying to both the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) and the Northern Travel Grant.

When I interviewed Tom about his donation of a kidney to his younger brother, I asked him about his experience with the Program for Reimbursing Expenses of Living Organ Donors (PRELOD). Tom explained that he was just starting the process and filling out the appropriate paperwork:

Because we're from Northern Ontario, they have the Northern Travel Grant. It's not just for donation. It's for any type of medical appointments that force you to leave your community, you get a travel grant. So all of our reimbursements have to go through that before they can go to PRELOD. So we haven't actually submitted anything to the PRELOD program, yet. We're hoping that when we get back from this trip that we'll have the stuff there that we'll be able to...if you were tight, you'd build up significant debt. It's different if you live in the community where you do it. When you start to go to remote places, like where we live, fairly remote areas. I probably took, on top of the whole thing, at least two or three other days off work just to get the testing done.

At the time of our interview, Tom and his wife were feeling the financial strain of having to travel between northern Ontario and Ottawa. Tom was also worried that the Program for Reimbursing Expenses of Living organ Donors (PRELOD) would not cover all of their expenses:

There are caps and Lisa (living donor coordinator) said that no one had ever gone over it and I thought that I would go over it, immediately. Because, I think, the travel limit was 1,500 dollars. I said, 'Well, we're going to blow that on one trip.' But because, I didn't realize that Northern Travel Grant would pick up all of that ahead of time, it actually won't be an issue. I don't think that PRELOD is going to actually pick up all that much.

When I interviewed Lisa, the living organ donor coordinator, she explained that she had never encountered a living organ donor whose expenses had gone over the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) \$5,500 cap. However, as Dr. Anderson observed some donors have to travel from other countries to donate so \$5,500 would not be sufficient, especially given an uncertain economy.

The Ottawa Hospital Renal Transplant Clinic attempts to control the reciprocal nature of giving the “gift of life,” by promoting the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) and the living organ donor gala. However, directed and

even non-directed donor narratives suggest that the “gift of life,” is reciprocated between donors and recipients outside of these “official” contexts provided by the Ottawa Hospital Renal Transplant Clinic.

Clinical Narrative On Reciprocity and Kidney Donation:

Reciprocity for the “gift of life,” does occur quite frequently between directed living organ donors and their recipients. During our interview Lisa, the living organ donor coordinator, mentioned that one of the grey areas of transplantation is this issue of compensation for the gift of a kidney:

Because obviously, you know, it is illegal for any money to be exchanged for the organ. I don't know necessarily that we can absolutely police something like that if it were to occur and who's to say that it is an exchange for the organ versus a Christmas gift, for instance.

Lisa's statement acknowledged that despite the Ottawa Hospital Renal Transplant Clinic's best efforts to control reciprocity for the “gift of life” it does occur between the donor and the recipient. Moreover, Lisa acknowledged that it is not necessarily bad to reciprocate for a gift given, but that monetary compensation for the gift of a kidney is clearly illegal and should be avoided. Lisa continued with her explanation of gifting outside of the clinic setting between directed donors and their recipients: “So, there's probably different interpretations and people have different slants on them, Just because they gave tickets to a cruise to their donor after the donation took place, do you call that compensation? Or, was it just a thank you?” Therefore, although the Ottawa Hospital Renal Transplant Clinic attempts to prevent reciprocity for the gift by referring to the kidney as an altruistic “gift of life,” and by limiting recognition for the contributions of donors to the organ donor gala and the Program for Reimbursing Expenses of Living

Organ Donors (PRELOD), reciprocity for giving the so-called “gift of life” still occurs between directed living organ donors and their recipients.

Donor Narrative on Reciprocity Within Kidney Donation:

Reciprocity for the “gift of life” takes on many different forms between recipients and directed living organ donors. Reciprocity between donors and recipients can be as simple as saying, ‘Thank you,’ and acknowledging that a gift was given and gratefully received. However, reciprocity can take the form of giving a gift in return for the gift of a kidney. Sometimes these gifts can be a representation of the donated kidney. For instance, Fred, who donated a kidney to his brother-in-law explained during our interview how his brother decaled a racecar with the image of the donated kidney.

My brother had the racecar decaled. I guess this was about 2 months after...we were over at a buddies place and he was helping him with his car and I wanted to go over and see what it looked like because our car was there in his garage. He says that ‘You have to help me take the cover off of the car’ ...and on the driver side is my name and beside my name is a kidney with an X through it...I thought that it was just great...so, I have a kidney with an X through it.

After Flora donated a kidney to her husband, she felt that he was not grateful for the kidney that she had given to him, which caused her to feel some resentment towards her husband:

He doesn’t show his emotions very much and I wanted him to thank me more and I would say it jokingly and sometimes I still do when he talks about it. I tell him, ‘You should kiss my feet or kiss the ground that I walk on,’ but jokingly. At first I thought...I wanted him to be more...but he was! He was! He owes his life to me.

Eventually, the resentment that Flora felt towards her husband went away when she realized that he expressed his gratitude towards her in his own unique way. After the

transplant, Flora's husband began to tell strangers that he had undergone a kidney transplant and he would proudly explain that Flora was his donor. Therefore, once Flora's husband acknowledged that his wife had given him a kidney that truly did embody her spirit, Flora's resentment subsided.

Amy's narrative also provides an example of reciprocity for the gift of a kidney. Amy explained that her recipient gave her a nice little gift on the morning before the transplant: "...(Stacy) and her husband came in and they gave me a little gift..." Every year since the transplant surgery, Amy and her recipient celebrate their anniversary and Amy's recipient always brings her a little gift: "And her children...they feel very close to me. I mean, they gave me a wonderful gift. I don't expect gifts...I always tell them...but they always give me a nice gift on our anniversary." Amy's comments about receiving little gifts from her recipient suggest that the gift of a kidney can be reciprocated.

Nola Johnson explained during our interview that she became closer to her sister Moira after the transplant and that Moira would often express her gratitude towards Nola for donating a kidney. Nola states that:

Moira always did extra things for me. I was the quieter of the two and she always went that little bit further for me. It was her way of thanking me. We never really...well, now and again she would say something...but not very often. We would just help each other along...

Reciprocation for the gift of a kidney was not limited to experience of directed living organ donors. Elizabeth, a non-directed living organ donor, explained during our interview that she had received a card and flowers from her recipient: "After my donation...the next day he sent me a dozen red roses, which was very sweet with a card

saying, not hand written, but with appreciation.” Elizabeth’s correspondence with her recipient was facilitated and monitored by the Ottawa Hospital Renal Transplant Clinic.

Resentment in the donor and recipient relationship can lead to what Fox and Swazey (1974, 1992) call the tyranny of the gift. Flora narrowly avoided the tyranny of the gift when she eventually realized that her husband was grateful for her gift of a kidney since he acknowledged the gift in front of strangers. Like Flora and her husband, my mother would constantly tell strangers that she had received a kidney transplant and that I was the donor. Although I was often embarrassed, I understood that this was how my mother wanted to express her gratitude and publically validate my experience as a kidney donor.

Directed living organ donors like Amy, Fred and Nola received gifts from their recipients, which prevents the tyranny of the gift from occurring. I suggest that the Ottawa Hospital Renal Transplant Clinic needs to acknowledge that reciprocity for the “gift of life,” does occur and that kidney donation is not necessarily altruistic and nor should it be referred to unequivocally as an altruistic act. The giving of an altruistic gift can cause the donor to feel resentment towards the recipient if the gift of a kidney is not acknowledged or reciprocated. Paradoxically, the medical discourse shared by the Ottawa Hospital Renal Transplant Clinic with the larger North American medical community is largely responsible for creating the tyranny of the gift by constructing the donated kidney as an altruistic “gift of life.”

Conclusion:

The donated kidney may be named, gendered and imbued with the personality traits of the donor. It seems that the gift of a kidney truly does embody the spirit of the person giving the gift (Mauss 1967). Moreover, some donor narratives portray the gift of a kidney as an ordinary, reciprocal Christmas or anniversary gift. In contrast, the Ottawa Hospital Renal Transplant Clinic views the kidney as a “gift of life,” which cannot be reciprocated. However, Lisa, the living organ donor coordinator suggests that the Ottawa Hospital Renal Transplant Clinic indirectly acknowledges that reciprocation for the gift of a kidney occurs between the donor and the recipient. The Ottawa Hospital Renal Transplant Clinic attempts to control reciprocation for the “gift of life” by hosting the living organ donor gala and promoting the Program for Reimbursing Expenses of Living Organ Donors (PRELOD).

Dr. Anderson’s narrative refers to the financial barriers that directed and non-directed living organ donors face throughout the organ donation and transplantation process. He suggests that the \$5,500 cap on the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) might not be sufficient for donors. Significantly, medical scholar Dr. Sally Satel (2008) advocates compensating living organ donors. Satel (2008) argues that paid compensation does not demoralize the donor nor will it entice a donor to donate for the wrong reasons. Satel states that:

[i]n reality, though, mixed motives are as likely to accompany “gifts” as they are to characterize paid acts—as, for example, in the case of a relative who gives a kidney out of guilt. Guilt may not be the ideal motivation for the gift—but it does not lessen the value of the organ to the recipient, and neither would compensation (2008: 69).

A regulated market in kidneys could increase living organ donation rates. However, even in Iran, a country that relies upon a regulated market in organs, the government cannot prevent gifting from occurring between recipients and donors (Ghods and Shekoufeh 2006; Malakoutian et al. 2007). Furthermore, Margaret Visser (2008) explains that it is commonly perceived that a return gift should be a different gift from the gift originally given, even though it should be of equal value. Visser also argues that, “ Money is less satisfactory than objects for the give-and-take of gifts; for one thing price is all that money is” (2008: 157). Therefore, I believe that even if donors were compensated financially for donating a kidney, reciprocation for the gift would continue to occur between the donor and the recipient.

In my view, the Ottawa Hospital Renal Transplant Clinic should acknowledge the social context in which the gifting of a kidney occurs between the donor and the recipient. However, if the Clinic is uncomfortable with directly acknowledging and accepting that reciprocity occurs between donors and recipients, the Clinic could avoid using the term “gift of life” when referring to organ donation and transplantation. As Jacques Derrida has observed, a gift must not be called a gift, and “It must not circulate, it must be exchanged, it must not in any case be exhausted, as a gift, by the process of exchange, by the movement of circulation of the circle in the form of return to the point of departure” (1992: 7). To refer to a gift as a gift means that it is caught up in a system of economic exchange (Derrida 1992). The true altruistic gift is the gift of friendship between two people. It is the relationship between two people that has value, which is only symbolized by the gift that is being given. The kidney symbolizes the relationship between two

people and the giving of a kidney is an acknowledgment to the recipient that they are significant and special to the donor. Ultimately, it is the relationship between directed living organ donors and their recipients that makes the organ donation and transplantation process a meaningful experience.

Chapter V

Conclusion.

In this thesis, I use Merleau-Ponty's (1962) phenomenological approach to argue that directed and non-directed living organ donors experience the organ donation and transplantation process through their bodies. Directed and non-directed living organ donors construct the organ donation and transplantation process as a meaningful undertaking because the act of donating an organ extends the life of another person, often a loved one, diagnosed with end-stage renal failure. Moreover, through narrative, directed and non-directed living organ donors are able to make sense of the organ donation and transplantation process and understand it as a meaningful experience (DeIVecchio-Good et al. 1992; Good 1994; Kleinman 1988, 2006; Mattingly and Garro 2000; Mattingly 1998).

Through educating themselves on the organ donation and transplantation process, directed and non-directed living organ donors become active participants in the medical encounter with the Ottawa Hospital Renal Transplant Clinic. Directed and non-directed living organ donors continue to be active participants in the medical encounter through negotiating with Clinic staff over dates for testing and surgery. However, following Scheper-Hughes's and Lock's (1987) concept of the body politic and Foucault's (1977, 1989) notion of the docile body, I show that directed and non-directed living organ donors become passive in the medical encounter with hospital staff during surgery and the post-operative recovery process.

Directed living organ donors negotiate with family members such as siblings or spouses in order to determine who will be designated as an organ donor. Support from family members is important for directed and non-directed living organ donors throughout the organ donation and transplantation process. However, if a donor feels that certain family members will not support their decision to donate, they may strategically neglect to inform these family members about the organ donation and transplantation process. Furthermore, as in Fred's narrative, the directed living organ donor may enlist the help of their extended family in order to convince a recipient to accept the offer of a kidney.

Finally, using Marcel Mauss's (1967) insight that a gift embodies the spirit of the person giving the gift, I argue that the gift of a kidney is an extension of the donor's self because it is named, gendered and imbued with the donor's personality. I also argue that a kidney is not an altruistic, "gift of life" but a gift that is reciprocated between donors and recipients like Christmas or anniversary gifts.

The Ottawa Hospital Renal Transplant Clinic refers to the kidney as a non-reciprocal, altruistic "gift of life." However, by hosting the living organ donor gala and through promoting the Program for Reimbursing the Expenses of Living Organ Donors (PRELOD) the Ottawa Hospital Renal Transplant Clinic indirectly acknowledges the reciprocal nature of "the gift of life."

Future of Organ Donation and Transplantation:

Daniel Asa Rose's (2009) non-fiction book, *Larry's Kidney*, is a darkly comedic story about how Rose helps his estranged cousin Larry secure an illegal organ transplant and a bride ordered by e-mail from China. At the beginning of the book, Larry is attempting to justify purchasing a kidney and states that:

For two years I've been on a dialysis machine four hours every other day, watching my life ebb away before my eyes. Solution number one is off the table, because I'm not about to ask anyone in the family for their kidney, given how much they dislike my guts, which I assure you is mutual. But solution number two is surprisingly doable (Rose 2009: 3).

Larry feels that the only way he can live his life is to illegally purchase a kidney. One hopes that this will not be the future of organ donation and transplantation in Canada.

A 2007 Citizen's Committee report determined that more than 17,000 people in Ontario were waiting for an organ transplant (Boadway et al. 2007: 2). The Ottawa Hospital organ and tissue donation website lists Canada as having one of the lowest organ donation rates of any industrialized nation (Organ and Tissue Donation Program, 2005, B). The Canadian Institute for Health Information determined that although the number of organ donors in Canada, "increased from 812 to 1,038 per year....the incidence rate of end-stage renal disease increased from 149 to 168 per million population" (Canadian Institute for Health Information 2009: 1). According to Lisa, the living organ donor coordinator at the Ottawa Hospital Renal Transplant Clinic, recipients from Ottawa can spend four to six years waiting for a cadaveric kidney transplant. However, living organ donation rates continue to increase in Canada, although outpaced by the increase in kidney disease (Canadian Institute for Health Information 2009).

Organ donation and transplantation is an emotional experience for those involved. Not everyone understands why someone would choose to donate a kidney. Perhaps the ambivalence associated with organ donation is best expressed by Amanda, who donated a kidney to her husband:

So, I think that people get uptight about their bodies because they don't see it as a multi-level, multi-purpose, different parts brought together. But they will go and spend money on a new nose, or a tummy tuck, or a boob job. There seems to be that Barbie-esque idea of I'll just put more plastic in it, but I would never imagine giving anything away...that bothers me because we are willing to have operations to pull our face skin back, but if someone needed a kidney—would you give it to them?

Contributions to Clinically Applied Anthropology:

At this point, I include a few suggestions about how the Ottawa Hospital Renal Transplant Clinic could improve the doctor-patient relationship. Dr. Anderson's narrative highlights the barriers to transplantation, since living organ donation rates have not fluctuated, while cadaveric donate rates have barely increased.³

Dr. Anderson also mentions the danger that Internet sites such as Living Donors Online pose for recipients. However, as Elizabeth's narrative suggests, Internet sites like Living Organ Donors Online can be useful for both donors and recipients. Moreover, according to Elizabeth, Internet sites like Living Organ Donors Online include information on living organ donation and a forum where donors can converse with one another. I would suggest that perhaps the Ottawa Hospital Renal Transplant could learn

³ The Canadian Institute for Health Information released a brief report in December of 2009 chronicling organ donor activity in Canada from 1999 to 2008. The report found that “[t]he average annual increase in deceased donors during the past decade was less than 2%” (Canadian Institute for Health Information 2009: 1).

from Internet sites like Living Donors Online. During our interview, Dr. Anderson was rather embarrassed to admit that the Ottawa Hospital Renal Transplant Clinic does not yet have a functioning Internet site where potential donors can learn about the risks and benefits of directed living organ donation. In creating a website for directed and non-directed living organ donors, the Ottawa Hospital Renal Transplant Clinic could consider including a forum where directed and non-directed living organ donors could discuss the organ donation and transplantation experience with one another, and where potential donors could connect with potential recipients. This forum could be monitored by the Clinic in order to prevent coercion and exploitation between donors and recipients.

Future Research:

In order to increase organ donation and transplantation in Ontario, areas of future research should include a thorough exploration of the educational and financial barriers to organ donation and transplantation. It would also be relevant to explore living organ donation from the perspective of the recipient in order to determine how they view the donated kidney. As I have discussed throughout this thesis, directed and non-directed donor narratives suggest that donors view the gift of a kidney as reciprocal. Further research needs to be conducted on how recipients reciprocate for the gift of a kidney. The voices of family members of donors and recipients also need to be heard, in order to determine if they construct the organ donation and transplantation process as meaningful. Finally, further ethnographic research would benefit from being multi-sited in order to reach a broad range of directed and non-directed living organ donors.

Appendix I

Questions for Living Organ Donors:

- 1) Tell me about yourself (age, occupation, background)
- 2) Are you donating your organ to a friend or family member?
- 3) Why do you want to donate your organ?
- 4) Please explain how you came to the decision to donate your organ?
- 5) What does donating an organ mean to you?
- 6) How do you feel about the donation process?
- 7) How did you start the donation process?
- 8) How did others (family, friends) react to your decision to donate your organ?
- 9) Can you please describe your current occupation?
- 10) Did you have to take time off of work?
- 11) Was your employer supportive of your decision to donate your organ?

Appendix II

Questions for The Transplant Nephrologist:

- 1) Tell me about yourself (how long have you been in your current position)
- 2) Can you describe your role/involvement in the organ donation process?
- 3) How many living related organ transplantations are you involved with in a year?
- 4) How many of those are successful?
- 5) Are there any long-term health effects associated with organ donation?
- 6) What types of barriers do potential organ donors face (health, occupation, family support) that can negatively compromise their ability to donate?
- 7) When does an organ donor cease to be considered one of your patients?
- 8) How would you describe the organ donation process to a potential organ donor?

Appendix III

Questions for The Living Organ Donor Coordinator:

- 1) Tell me about yourself (How long have you been in your current position)?
- 2) Can you please describe your role/involvement in the organ donation process?
- 3) How many living related transplantations are performed a year?
- 4) How do you approach a potential organ donor?
- 5) How would you educate a potential donor about the benefits of organ donation?
- 6) What are the benefits of organ donation?
- 7) What are the potential problems (health, occupation, family support) that can impede organ donation?

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