

Structured Forgetting and the Social Organization of Kidney Exchange in Ontario

by

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Abstract

Theoretical resources regarding the creation of objects and orientations in ideology and material practice are drawn on to develop an original, theoretical account of organ transplantation. This analytical lens is then used to advance understanding of the social relations that enable and inhibit the exchange of kidneys for transplantation. The argument is that customary claims about how to increase organ donation, set within an altruism versus market framework, deflect attention from a significant variable: the legitimacy and limits of removing kidneys from their owners – in other words, alienability. Two sets of rules are revealed, with one set, the rules of altruism, requiring and eliciting public engagement, and the other set, the rules of alienability, being pushed by experts within their realm of authority. Both sets of rules demarcate boundary lines through a fundamental tension between recipients, intermediaries and donors that is demonstrated to be imbalanced by a recipient-centric orientation. As a result, public discourse is focused on a small set of variables and distanced from a far more complex set of dynamics predominantly emerging from the relationality of donors and recipients.

Seeing the deflection of attention challenges both the legitimacy of conventional wisdom about transplantation, especially as it informs public policy, and the common view of a complete distinction differentiating altruism from capitalist modes of body part exchange. It also raises new questions about persuasion and public knowledge that trouble altruism, and shows how efforts to alleviate the suffering of some, (potential) recipients, has largely unintentionally led to a *structured forgetting* of the suffering of others, (potential) donors. This is demonstrated for both deceased donation and living donation using a case study of one organ, the kidney, in one jurisdiction, Ontario, Canada, from 2000 to 2014, with a focus on donors and intermediaries.

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Glossary

CBS. Canadian Blood Services.

CCDT. Canadian Council for Donation and Transplantation (2002–2006).

CORR. Canadian Organ Replacement Register.

DCD. Donation after Cardiocirculatory Death (aka heart death).

DPMP. Deceased donors per million population.

ESRD. End-stage renal disease (aka End-Stage Kidney Disease, ESKD).

ICU/CCU. Intensive care unit/critical care unit (neurosurgical and trauma centres).

LDPE. Living donor paired exchange.

NDD. Neurological determination of death (aka brain death).

Nephrectomy. Surgical removal of a kidney.

OPO. Organ procurement organization.

TGLN. Trillium Gift of Life Network.

TTS. The Transplantation Society.

UN. United Nations.

WHO. World Health Organization.

Chapter 1 Introduction

This dissertation is about kidney transplantation. It is an empirically-driven research study of the organization of the giving and receiving of human organs, especially the determination of who can give, how kidneys are asked for, relinquished and received, and how such exchanges are understood and decided upon. A case study design is used to compare the deceased and living donation systems for one organ, the kidney, in one (explicit consent) jurisdiction, the province of Ontario, in a federal country, Canada, from 2000 to 2014. The focus is on donors – both deceased and living – and the role of intermediaries (transplant centres and the provincial organ procurement organization, Trillium Gift of Life Network (TGLN), working in the context of national and international level organizations and actors).

I open the introduction with a story that captures the pattern of developments in Ontario with respect to deceased organ donation and living organ donation during the period under study. Illustrated is a particular sociological puzzle of disjuncture between public understanding and expert knowledge and action. The subsequent section shows that this phenomenon is occurring in similar jurisdictions. These pieces lay the groundwork for explaining the location of the study within social science scholarship, the theoretical approach, guiding questions, the central claim, and the implications that follow from the research findings. Details then follow regarding how the study was conducted, the contribution of the research and how the findings are presented in the chapters. I conclude by acknowledging my premises, biases and use of terminology.

1.1 Sociological Puzzles that Arise from Ontario's Investment in Organ Donation

In the year 2000, the Honourable Mike Harris, then Premier of Ontario, chose organ donation as an important public policy investment. In his Speech from the Throne, the Premier promised to double the annual organ deceased donor rate for deceased donors in five years, from 150 to 300 donors (Priest, 2000). Media coverage cited Premier Mike Harris declaring that “the current organ donation system is ‘too complex’ and is failing to meet the growing demand for transplants. ‘It’s a system that we are determined to fix’” (Boyle, 2000). As a result, the province increased funding for organ donation to more than \$120 million from \$47 million by 2005 with part of the money earmarked for an advertising campaign “to get Ontarians talking about organ donation so they make their intentions known to their relatives” (Boyle, 2000).

The double-the-donor-rate commitment was reported in the media as good news. It was heralded as “new hope for 1,720 Ontarians awaiting transplants,” and was strongly endorsed by donor families and recipients (Boyle, 2000). Quoted in the media from the press release and in the report that followed, Harris claimed that not only was the organ shortage a crisis but that this was especially the case in Ontario where the annual deceased organ donor rate at 14.1 donors per million population paled in comparison to 33.8 in Pennsylvania and 33.6 in Spain (Boyle, 2000; Ontario, 2000). Two solutions to this problem were identified: increasing consent to donation and increasing hospital efficacy. Present in the media coverage and, as we see, in the advisory committee report that follows

was a caveat: “only a small fraction [...] would have been eligible donors because they were not first brain dead.” But this limitation only fuelled the need to ensure, “organ and tissue donation opportunities are identified” (Priest, 2000). The plan was to first establish a new central agency, an organ procurement organization, Trillium Gift of Life Network (TGLN) and then, 18 months later introduce a routine-referral law that would require hospitals to notify the agency of all brain deaths and imminent deaths.

With this, Premier Harris established an era of investment in deceased organ (and later tissue) donation and transplantation. At the core of the public discourse that emerged was a claim that became conventional: that the low deceased donor rate – especially low in Ontario – is a crisis of generosity and failure of the healthcare system that could and should be fixed. If the deceased donor rate was higher in other jurisdictions, it could be higher in Ontario. In being framed in this way, organ donation was articulated following what I interpret to be a discourse of donation that establishes organ exchange through transplantation as a moral cause.

Beneath all the enthusiasm, a few experts asked, “is it possible to raise the volume of organs from deceased donors?” Two reports released in 2000 by a demographer and outsider to transplantation, David Baxter (one with Jim Smerdon), disagreed with the claim that the annual deceased donor rate could be doubled. Their research found that the problem was not system performance but the size of the pool of potential deceased donors. Increases in the deceased donor rate could only occur at the margins. Plus, the pool of potential donors was shrinking in size. Baxter’s research was ignored; however, the report produced by Premier Harris’ Advisory Board on Organ and Tissue Donation (assembled *after* the

Premier's Speech from the Throne) with recommendations on how to double the rate quietly included a disclaimer, "There is one caveat to Ontario's ability to achieve its goal...Ontario may have fewer potential donors than the most successful jurisdictions" (Ontario, 2000: 22).

The pattern of public enthusiasm and marginalized disclaimers located in the fine print of public policy reports marks the course of Ontario's investment and engagement with organ exchange over a fourteen year period, 2000-2014. TGLN focused exclusively on deceased donation and the public was engaged, extensively, in deliberating upon the problem of Ontario's especially low organ donor rate. As organ donation gained an unprecedented political salience, continuous campaigns exhorted the public to consent in advance to deceased donation, and politicians scrambled to pose as the champion of the cause. Public deliberations over what was most important in securing consent shifted from signing an organ donor card and sharing one's wishes with their family, to an inquiry and rejection of adopting presumed consent (instead of the current explicit consent system), to establishing an affirmative electronic registry to ensure that families honour individual wishes. Public reports in 2007 and 2009 kept the public focus on consent, with hospital efficacy as a secondary concern. Around this time, TGLN's goal started to use the language of promoting a "culture of donation" in Ontario, both in the public at large and in intensive care units where deceased organ donation takes place.

The effect of the public focus on consent was to foster the impression that the rise or fall of the deceased donor rate rested almost exclusively on consent to organ donation. As a result, an insufficient rise in the deceased donor rate could easily be interpreted to be

a failure of altruism, the central pillar of public policy. The corollary, then, increasingly asserted over this time period, was that if altruism was insufficient, voluntary giving would have to be abandoned by offering monetary incentives to organ donors. The identity of Ontario and Canada as an altruistic nation appeared to be on the line and the marginalization of other potential explanations left little ground for objection other than through appeals to altruism.

Yet another site of politics plays out during this time period for which the year 2006 is pivotal. While the public focus remained steadfast on consent, TGLN made two significant changes in the middle of the decade that gave credence to Baxter's finding that the pool of potential deceased donors was limited. Starting in 2005, TGLN joined with national colleagues to enlarge the size of the deceased donor pool by changing the definition of death. A national Canadian Council for Donation and Transplantation (CCDT) conference of experts released guidelines recommending hospitals develop protocols for "DCD" which stood for "Donation after Cardiocirculatory Death." By counting, as death, signs of the heart desisting rather than tests of the brain, more dying patients could qualify to donate. Expanding the size of the potential deceased donor pool was a TGLN goal identified in their strategic and business plans. While described as expanding opportunities to donate desired by the public, classifying more patients as potential donors expanded TGLN's opportunity to meet their goal of doubling the annual deceased donor rate.

TGLN also followed in the footsteps of their American counterparts by introducing a different way to measure the deceased donor rate. Rather than rely on the standard

measure of *donors per million population*, the organization established a conversion metric counting the number of potential donors who become actual donors. This provided TGLN with both a meaningful tool to measure their own performance, and a means to defend their work against the criticism of being unable to meet deceased donor rate expectations.

These two changes by TGLN – redefining death and developing a new performance measure – remained virtually out-of-sight of the public focus on consent even though the changes had profound societal and organizational implications. Shifts in the signs taken to signal that patients are either alive or dead is of obvious significance. As an organization with a mandate to supply organs, TGLN, like all organ procurement organizations, was fully dependent upon the size of the pool of potential donors they had to work with; they could only aim to convert every potential donor into an actual donor to satisfy their *raison d'être*. Measuring the pool using a conversion metric – unlike *donors per million population* – recognized the limit to the scope of TGLN's work. Yet, the definition of death and size of the pool of potential deceased donors did not garner public attention, nor did TGLN draw attention to these developments. The conversion rate performance measure did not move beyond the depths of annual reports and failed to be part of the evidence analyzed in either the 2007 or 2009 public inquiries in Ontario's low organ donor rate. In their organ donation campaigns, TGLN promoted another new measure instead, "every three days someone dies waiting for an organ transplant," while media stories, transplant physicians, and federal politicians continued to use *donors per million population* consistently throughout this period.

Over the period under study, 2000-2014, TGLN added almost 100 more deceased donors per year, reaching a new high of 247 deceased donors in 2013 for close to 1000 transplants of all organs per year. However, even with extensive investment at the cost of over 11 million dollars per year, Ontario fell 53 donors short of the “doubling” the rate goal of 300 (TGLN, 2013). The goal and effort to double the annual deceased donor rate therefore constitutes a public policy failure.

A similar pattern of dissonance between what is in the public eye and significant shifts taken by kidney exchange intermediaries characterizes the domain of living donation in Ontario. As the public debated explicit versus presumed consent for deceased donation, experts met and changed the rules regarding living donor eligibility criteria. In 2006, CCDT sponsored a national forum on living donation where experts established medical guidelines. The guidelines (along with others developed during this period), set limits of donor protection that constrained and legitimized the broadening of living donor eligibility criteria. In keeping with a longer process of expanding who counts as kin, novel donors became permissible as did compensating living donors for their expenses. With media coverage of only positive tales, the group that remains invisible among Ontario’s living donors are those who experience adverse outcomes, such as Julie, interviewed in this study, who was told by her family doctor, “the health profession let you down,” in approving her as a kidney donor.

One interpretation of the pattern observed, that forms the premise of this dissertation, is of a disjuncture that lies along an axis dividing public knowledge from expert action. When consent (and hospital efficacy) are put in context within a broader framework of all

of the variables that influence processes of objectification attendant to transplantation, the significance of the two variables that receive greatest public attention is diminished. And, the urgency to take action is countered by the challenge of what to do. “There is a strong desire for ‘magic bullet’ solutions,” a key informant told me, which is diffused by seeing the complexity of the task. Further, while the public is engaged consistently over fourteen years in debating certain rules – especially rules about consent to organ donation, – and, more recently, the role of money, the public is not engaged in considering the shifts made to other rules, of alienability, regarding donor eligibility criteria. In other words, what is notable is less the public policy failure in and of itself than the fact that neither the policy failure nor the changing of the rules receive public scrutiny. My analysis of what has occurred in Ontario offers a critique of the conventional wisdom that the reason for an insufficient supply of kidneys is a lack of altruism.

1.1.1 Ontario as Emblematic

This is not the first time nor am I the only one to notice the absence of public scrutiny and debate where it appears warranted. The conventional wisdom regarding organ transplantation is that this therapeutic modality saves lives but is hampered from reaching its full potential because there are not enough organs to meet demand. Moreover, this is “a problem that should not be a problem” because organs are claimed to be available if only people would consent to donate and hospital medical providers intervened effectively (Satel, 2008d). Yet, in the same fashion as demographer David Baxter, two sociologists, Keiran Healy and Graciela Nowenstein, also found in their research that public policy

debates lacked a foundation in evidence. They entered the topic of organ transplantation at the height of public discourse in the United States, Canada and Europe calling for presumed rather than explicit consent as the answer to the problem of insufficient organ supply.

Keiran Healy (2006a, 2006d) shares with many scholars the use of Richard Titmuss's (1970) book, *The Gift Relationship: from Human Blood to Social Policy* as a touchstone. In Healy's view, the promise of Titmuss's approach of comparative, national research has not been realized, nor does it inform public debate. Research on cross-national variability in deceased donor rates, especially, does not receive the attention it deserves. Ethical arguments and simplistic positive correlations between high rates of deceased donation and presumed consent systems take the place of empirical investigation. "The assumption is that once the overall exchange system is fixed, certain consequences for the volume and composition of the supply will tend to follow" (Healy, 2006a: 1017). Healy fills this gap by doing research on variability in rates to find that debates and claims regarding consent mislead our thinking about what makes a difference in the organ supply. It is organizational differences that matter instead.

Graciela Nowenstein (2013) similarly critiques the dominant ethical and policy debate focus on donor incentives, specifically the lack of evidence to support the claim that either a market or presumed consent—less or more state power—will result in a higher deceased donor organ supply. She cites a 1998 article in *The Lancet* in which the authors acknowledge that non-legal variables influence procurement rates yet assert the superiority of presumed consent systems. There is a lack of empirical evidence, even by renowned experts, to support the claim of a causal relationship between a legal donation regime

(presumed consent) and organ donation rates. Nowenstein comments on how compelling the visual evidence appears: a bar chart of deceased donor rates per million population comparing countries with presumed consent versus explicit consent systems. Such representations illustrate “how obvious the idea that consent legislation is a fundamental independent variable in explaining differences in procurement rates can appear at first sight” (Nowenstein, 2013: 20). However, reviewing each of the top three countries identified, Nowenstein easily shows that the consent system cannot be disentangled as an independent variable and does not even fit, chronologically, in all cases with increases in national donor rates. She concludes that support for presumed consent, “ultimately rests on an assumed and unverified connection between procurement rates and consent legislation” (Nowenstein, 2013: 21).¹

Casting a wider lens on the absence of public criticism, a number of social science scholars in the field have observed over decades a drive to transplant that obscures aspects of what is at stake. Lesley Sharp opens her latest book describing this orientation in thinking as ‘the transplant imaginary’:

The field itself is readily and widely imagined as plagued by unwarranted suffering, where concerns may *focus nearly exclusively on the needs of dying patients* yet not, for instance, on broader health disparities that shape the calculus of heart or lung disease, liver failure, or diabetes, on the circumstances of donors’ sudden or even violent deaths, or on the often insurmountable, lifetime costs accompanying the promise of a ‘second life’ won through the transplantation of a new organ. When framed this way, organ transfer is rife with ‘if only’ statements: if only there were more willing donors; if only presumed

¹ What is more, both authors note that presumed consent is not applied in practice, effectively dissolving the distinction between the two systems.

consent legislation could prevail, if only viable, alternative sources existed for scarce human body parts. (Sharp, 2014: 25, emphasis added)

The public and policy view of the problem is narrow and the answers are simplistic. Thirteen years prior, in 2001, Nancy Scheper-Hughes made a related criticism, pointing out an imbalance in public knowledge of donors versus recipients.

Dialysis and transplant patients are visible to us. We see and hear their pain and suffering. Their stories are shown to us in the media. But while there is empathy—even a kind of surplus empathy—for one population—the transplant patient—*there is a deficit or an absence of empathy for the groups we cannot see, those whose lives and suffering remain largely hidden from view—the population of organs and tissue donors, living and dead* (Scheper-Hughes, 2001: 53, emphasis added).

For her, this disproportion in powerful narratives and visibility contribute to what she called a ‘structured forgetting’ of organ origins. In research on commercial kidney markets, Scheper-Hughes (2001: 53) found that few recipients knew anything about “the kinds of demands that are made on the bodies of ‘the other, living or dead’”. Further, she noted that this forgetting is also found within altruistic systems; it is not unique to markets. In borrowing her term, ‘structured forgetting,’ I credit her, along with other scholars, for their critical eye in uncovering and raising concerns about imbalances in how transplantation is thought about and conducted.

A decade prior, ethnographers Renée Fox and Judith P. Swazey (1992) expressed alarm that the field of transplantation in the United States had changed in the 1980s. The pair perceived a disjuncture between a positive public portrayal of organs as gifts and transplantation as a miracle concealing a hubris-ridden drive to expand transplantation that refuses to accept what theologian Gerald McKenny (1997) calls the limits of finitude.

Finally, my own entry into this topic was through an effort to understand why and how questioning the concept of brain death was not tolerated at a public policy event in Canada in 1999. My Master of Arts thesis, completed at the end of 2000, examined an exchange that took place during a national public inquiry by Members of Parliament into the problem of organ and tissue shortage conducted by Canada's House of Commons, Standing Committee on Health (McKay, 2001).² In an unplanned departure from the intent of the Members of Parliament who initiated the inquiry, three doctors testified before the committee that brain death is not death. In my thesis, I interpreted this as a 'breaching moment': I found containment of the dissent from the usual framing of the problem to be revealing. The breach opened up a 'black box' which resulted in a few newspaper articles but was otherwise quickly countered and dismissed by numerous transplant experts as an "unfortunate distraction from the real issues" (Canada, 1999a). I asked, how was it possible to marginalize a challenge to the central premise of deceased donor transplantation—that organs are removed from persons who are dead? (McKay, 2001). This too was an instance of noticing strained and even disquieting social relations within the altruistic system of exchanging organs.

Thus, it is not only in Ontario that organ transplantation within altruistic regimes appears to be more complex than portrayed by conventional wisdom. What other scholars and my previous work have in common is the identification of a disappointment and a

² The public hearings were conducted as a study by the Standing Committee on Health called "The State of Organ and Tissue Donation in Canada." The report produced is titled, "Organ and Tissue Donation and Transplantation: A Canadian Approach" (Canada, 1999c).

puzzle. It appears that some of the standards of public policymaking in a democracy – such as open debate, an evidence-base, and accountability, – are missing. The puzzle is: to what extent is this the case, why is this happening, and with what implications?

1.2 Relevant Scholarship and My Theoretical Approach

My study is specifically located within a small set of literature on the topic of organ transplantation. Recent country specific ethnographies include Sherine Hamdy's (2012) study of End-Stage Renal Disease patients in Egypt, Marie-Andrée Jacob's (2012) study of living donor kidney exchange in Israel, and Gabrielle Nowenstein's (2013) diachronic research on presumed consent in France. For his analysis of donors and the organization of exchange, this study draws inspiration from Richard Titmuss's (1970) comparative study of blood systems. And, among others identified in the literature review (in chapter 2), theoretical work on organ exchange includes Lawrence Cohen's (2005) analysis of the 'bioavailability' of some women as kidney sellers in India, and, economic sociology research by Keiran Healy (2006d) and Philippe Steiner (2010).

Theoretically, the study reflects the sociological sub-disciplines of Canadian political economy and critical sociology of health and medicine. From the former, I bring academic training in analyzing hierarchical social relations of gender, class and race, usually in relation to the state, to bear on how the exchange of kidneys is organized at a societal level. With respect to the latter, my approach is consistent with and takes inspiration from the writings of Monica J. Casper and Lisa Jean Moore (2009) as well as Jonathan M. Metz (2010) and his edited collection with Anna Kirkland (2010). These four

scholars, among others, advance critical analyses that are largely inspired by the work of Michel Foucault on biopolitics (see, among other work, Foucault, 2002 [1966]; Lemke, 2011). This complements the Foucauldian approach I took in my previous research, completed in 2001, which drew especially on the work of Nikolas Rose (1994).

Bearing this scholarly training in mind, I nonetheless found an inability to satisfactorily interpret my findings through various existing theoretical frameworks. This eventually compelled me to develop my own theoretical account of how organ transplantation works. Informing my account are two broad sets of scholarship, which I categorize as: 1) the process approach within commodification theory and the conceptual tools of rules and boundaries; 2) theories of knowledge as directed and dominant. Specific scholars within the first category include Igor Kopytoff (1986), Ian Hacking (1986) and Bruno Latour (1993). The second category draws more abstractly from the vast scope of social theory that articulates how any given group of people come to think and act towards another group, and the ideological basis of forms of domination. My research findings, especially on deceased donation, also draw on select critiques of altruism by sociologists Jacques Godbout with Alain Callé (1998) and to a lesser extent, Naomi N. Duke (2013) and L. Song Richardson (2013).

1.2.1 Research Questions

Given my problematic of a disjuncture between public discourse and how kidney exchange works in altruistic regimes, and an emphasis on three pieces of a larger puzzle – asking for kidneys, the point of view of donors, and mezzo-level actors, – I chose a broad

question to guide the research conducted for this study: what are the social relations that enable and inhibit kidney exchange for transplantation? Sub-questions include: when is asking for or offering a kidney appropriate? As a society, how aggressive should we be and are we aggressive enough in seeking kidneys to heal ourselves and our friends? Through these questions, applied to this case, I sought a deeper understanding of altruism as a mode of exchange.

1.2.2 Central Claim

My findings reveal first that there is a tension between donors, recipients and intermediaries that is imbalanced by a recipient-centric orientation. Second, the focus on increasing organ donation, set within an altruism versus market framework, deflects attention from a significant variable: the legitimacy and limits of removing kidneys from their owners – in other words, alienability.

1.2.3 Implications and Contribution

The implication of the findings of this study are that those who stand within the logic of the moral cause of organ donation are less attuned to the full scope of challenges to finding and creating a sufficient number of kidney donors. As a result, arguments made that emphasize consent or hospital efficacy as means to increase supply – whether altruistic or pro-market – hold less promise than is recognized. For example, while it matters whether consent is genuine, obliged, presumed or purchased, the donor rate nevertheless depends on the number of people who meet all of the other deceased or living donor eligibility

criteria: dying a specific way on a ventilator and, for both dying and living persons, being in good health. The public is thus left out of aspects of organ exchange that are not related to consent but are equally, if not more, important. What this does is draw attention away from non-standard considerations such as how lines around donor eligibility criteria are drawn, who ought to draw them and upon what authority.

At the broadest level, this study contributes to scholarship that examines how we are ‘becoming medicine’ by analyzing what is at stake, how the exchange of body parts to heal others is organized and governed, and to what effect. As many scholars have noted, there is a rise in the exchange body parts – kidneys, ova, hair, *et cetera* – as things that have value, apart from persons. Not a week passes without a media story about some body part, be it a tissue or an organ in need or received, punctuated by the occasional world-first transplant (the latest being the uterus and before that a face) and the occasional scandal story of organs taken, profit made and sellers harmed. The standard narrative emphasizes a problem of insufficient supply for which the answer is the moral imperative to generate more organs. This study challenges conventional thinking, and in doing so advances understanding of current developments.

1.3 The Study

This part of the introduction briefly describes the design of the study which is detailed in chapter 2. As stated above I use a case study to compare deceased and living donation within one jurisdiction, Ontario, Canada over the time period of 2000 to 2014. The inclusion of both deceased donation and living donation is unique; aside from the work

of Philippe Steiner, I have yet to see both donor types included in social science studies of transplantation. Given this breadth, the study is isolated to one organ, the kidney, and priority is given to one level of analysis, the mezzo-scale of intermediaries, situated within levels of governance above and below. Intermediaries include: most directly, renal transplant centres and Ontario's organ procurement organization, Trillium Gift of Life Network. A secondary mediating role is played during the period under study by national-level institutional actors, the Canadian Council for Donation and Transplantation (2002-2006) and Canadian Blood Services.

The data analyzed fall into three categories. First, textual sources include annual reports on organ donation and transplantation produced by the intermediaries listed above as well as policy and protocol documents from three of Ontario's renal transplant centres. Three provincial inquiries on the problem of the shortage of organs for transplantation produced in 2000, 2007 and 2009 are analyzed extensively. Similar reports produced prior and following this set or by the federal government are given lesser attention along with media reports and websites. Second, descriptive statistics are used to construct a profile of Ontario's organ providers. Third, interviews were conducted with thirty-four individuals between July 2010 and April 2011 as an exemplary rather than representative sample of direct participants (living donors, a donor family and recipients, both actual and potential) and intermediaries (staff at TGLN and three renal transplant centres). One participant observation was also conducted of the 2011 annual TGLN donor family medal ceremony. The data analysis process followed the principles of grounded theory Glaser and Strauss

(1967), integrating all data sources, and was iterative. My theoretical account of transplantation was therefore arrived at last.

1.3.1 Chapter Outline

The chapters that follow unfold by first situating the research and describing the study. Then comes my theoretical account of how transplantation works, followed by identifying Ontario's kidney exchange recipients and donors, and the structure of two organ procurement systems – deceased donor *community altruism* and living donor *intimate altruism*. It then shifts to four substantive chapters that demonstrate how attention is drawn away from complexity in deceased donation and how the tension between donors, intermediaries and recipients is negotiated and boundaries pushed in living donation. As deceased and living donation are distinct from one another on a number of counts, especially in how they are governed, I separate my analysis of each into two chapters for deceased donation (chapters 5 and 6) followed by two on living donation (chapters 7 and 8).

To elaborate, the next chapter, Chapter 2, presents a review of relevant literature followed by the theoretical and methodological approach and details of data collection and analysis. The scholarship on body part exchange is demonstrated to be dominated by a dichotomous framework of altruism versus markets which originates in this field in the work of Richard Titmuss in 1970. I identify four streams of critical literature emerging since this time, each of which is shaped by the dichotomy, and locate my study within the call for analyses that probe 'beyond the binary' of this framework. I then turn to my

intervention by detailing what informs this study. Social theories found useful to interpreting my data are identified and elaborated upon (as identified above). The dataset relied upon and process of analyses is also explained. I close this chapter by noting the limitations of the study.

Chapter 3 begins my contribution by offering an original theoretical account of how transplantation works. I argue that kidney exchange is complex with respect to donors for several reasons, most importantly because of the tension that is created between the demand for kidneys and the constraints on its supply: kidneys must be relinquished without causing harm. Using legislation as evidence I identify a recognition that valuing kidneys ahead of persons is an inherent threat that underpins the social relations of body part exchange. To conceptualize how this threat is managed, I discern a process of objectification that entails three parts: 1) establishing a source of organs, in other words a pool of potential donors from the living and dying; 2) governing rules of altruism and alienability to establish and limit the pool; and 3) techniques of converting potential donors into actual donors. Herein lies a tension between the interests of recipients, intermediaries and donors and a recipient-centric orientation that is pervasive in the pursuit of transplantation yet contested by the assertion of donor protection.

The altruism versus market oppositional framework contests only market transactions, positioning altruistic exchanges as unproblematic, even aspirational. The effect of this dualist framing is it to impoverish analyses of altruism. My claim is that a tension between primary parties exists regardless of the mode of exchange – in altruistic exchanges as well as in market exchanges. Thus, rather than a ‘on’ or ‘off’ model, reflecting

the dichotomy, establishing some exchanges as ethical and others not, using money as the marker, my tension model suggests a continuum of orientation and action. It also applies at different levels: interpersonal, intermediaries and societal. Here the intermediary and societal levels are the focus.

I make this argument through an interpretation of the historical development of transplantation that lays emphasis on three turning points each of which opened up new pools of potential donors. The evolution of Ontario's Human Tissue Gift Acts is also identified as a useful point of reference for differentiating the forms of authority central to governance of organ exchanges. The two variables I ascertain as most determinative of kidney exchange in Ontario are altruism and alienability – the terms of exchange and legitimacy of organ removal. This shifts the dominant frame of reference by bringing alienability into view. I understand altruism as the exchange of a kidney for psychological benefit, and alienability as the legitimacy of removing one or both kidneys on the grounds that this organ is not too precious or vital to the life of the donor. Further, I categorize altruism as a 'rigid' rule, as it requires legislation for significant change, and alienability as a 'pliable' rule, since the intermediary of the medical science community is granted authority to change these rules without public engagement.

Chapter 4 extends the overview of how transplantation works by shifting from theorizing to a quantitative description of how kidneys are exchanged in Ontario. This is done for both deceased donation and living donation to paint a picture of the societal-level relationality between recipients and donors. The profile of kidney donors presented is thereby original in its comprehensiveness. It includes a profile of living kidney donors that

captures who gives kidneys to Ontarians at transplant centres in the province as well as to Ontarians through commercial exchanges in other jurisdictions, and the primary diagnoses of deceased kidney donors. Although this chapter is largely descriptive, aspects of the argument of the thesis are evident, specifically the broadening of donor eligibility criteria initiated in 2006. Other matters included explain: End-Stage Renal Disease, the complexity of immunological compatibility. I argue that organ transplantation needs to be understood as a therapeutic modality with two parts: organs and a daily pharmacological regime. The chapter ends by detailing the similarities and differences in governance between the two systems of exchange: deceased donation and living donation.

Chapters 5 and 6 on deceased donation *community altruism* demonstrate how the public emphasis on aspects of the rules of altruism – especially consent and hospital efficacy – deflect attention from a more fulsome understanding of organ transplantation, especially an appreciation of the limits of alienability. In chapter 5 I analyze the central messages of a ‘discourse of donation’ that interpolates the public to adopt a recipient-centric orientation. I show how the dominant knowledge came about, its core messages, sources, shifts in emphasis over time, and how it influences public understanding and public policy. I draw on media sources, public policy reports and interview data to demonstrate my claims.

Chapter 6 calls attention to other aspects of deceased donor *community altruism* that are virtually excluded from the public realm. TGLN’s work in hospital Intensive Care Units and Critical Care Units (ICU/CCUs) to establish organ donation services is detailed and recipient-centric – donor protection tension in implementing donor services is identified.

In this section I demonstrate that the pool of potential donors is too small to generate enough organs to meet the deceased donor wait list for kidney transplantation. A conversion rate is also compared to the donors per million measure and TGLN's performance assessed on their own terms. Two case studies are then drawn on to further reveal the recipient-centric-donor protection tension in deceased donation that is not evident through the lens of the discourse of donation. Alienability is front-and-centre in these cases. The first is with respect to individual deceased donors in controversies over what constitutes death, and the second in disputation over recognizing the population of deceased donors in measuring the deceased donor rate. Finally, more insight on how 'structured forgetting' arises is provided in a case whereby a transplant physician 'sees' potential donors' deaths as unnecessary, counter to the dominant narrative that naturalizes these deaths.

Chapters 7 and 8 turn to living donation which receives less public attention, is governed differently, and the challenges of imbalanced tension between donors, intermediaries and recipients are more apparent. As I explain in chapter 4, living donation is decentralized and regulated by the state. The key site is the transplant centre where the institution and physicians are guided by professional practice norms and rules established at the national and supra-national levels. Through my theoretical lens, what we see across the two chapters is a quest to 'find the line' that allows living donor organ exchange to expand "ethically." As we saw in deceased donation, the visible contestation is over the terms of exchange of altruism and the less visible but more pliable rules of alienability are staked out and shift largely out of public view.

Dividing the two chapters by level-of-analysis, chapter 7 analyzes the supra-national and national level. During the study period, transplant abuses lead to efforts to protect donors and maintain the legitimacy of transplantation. There are two efforts: an anti-transplant abuse campaign and the release of several professional practice guidelines. I argue that the medical practice guidelines – pliable rules in *Gift Acts* – delimit in a way that enables living donation to proceed and expand.

Chapter 8 examines how kidney exchanges work in practice at the local and national/provincial levels. We see that coming to know the donor is key to upholding “ethical” living donor kidney exchanges at transplant centres in Ontario. I identify four categories of new donors in Ontario and show how the logic of recipient-centrism pushes boundaries. As a result potential living donor eligibility criteria are loosened with the effect of expanding the pool of potential living donors to increase the volume of kidneys available.

The conclusion returns to the primary research question of what enables and inhibits kidney exchange for transplantation. I summarize the findings and review the implications of the study. More specifically, based on my analysis of deceased donation and living donation, I review my contribution to advancing critical scholarship on organ exchange more generally and of altruism – how it is defined, how it functions as a form of protection for donors as well as intermediaries and recipients and the downside of deflecting attention from the complexity of kidney exchange for transplantation. I also identify areas revealed herein where more research is needed to advance understanding of kidney exchange for transplantation.

1.3.2 Biases, Premises and a Note to Readers

My bias is in favour of altruism as opposed to authoritarian or capitalist markets, and in favour of finding conscientious ways to heal people who are suffering, including through kidney exchange. More than anything, I am in favour of conducting body part exchanges in a more transparent and balanced fashion that recognizes the tension I claim is inherent in these social relations.

Lest there be any confusion, I consider recipient-centrism to be not only necessarily inherent to kidney exchange – and many, if not all, kinds of body part exchange – but a good thing. For full disclosure, I need only look at my own two children to be grateful for recipient-centrism. Thoughts of me, as a potential recipient, intervened sufficiently in the (sex) lives of my donors to enable the exchange through which they were conceived. It is the degree of recipient-centrism that matters, for it can have a negative, even exploitative, effect when it threatens to shift the value of the kidney – or any body part – ahead of the value of the person.

Part of my motivation for making these statements is the awareness (and concern) that my training in critiquing social relations casts too negative a view throughout the thesis, and for this I apologize for not having more time to edit enough to strike the right balance. I employ two strategies in an attempt to counter the tendency of an academic critique coming across as condemning instead of what I intend which is neutrality, notwithstanding the biases identified above. Occasionally, and intentionally I add explicitly positive statements to signal that my use of any particular descriptor, such as the word

objectification, is not disapproving. In places this may appear contradictory; sure enough, my interpretation of the findings revealed many instances where a positive, genuine instance of solidarity, for example, also unintentionally contributes to a larger phenomenon of less positive consequences. With respect to terminology, a glossary is provided to help navigate the many terms and acronyms used in the field and in the study. I treat a number of descriptive terms as interchangeable synonyms even though many words in the field of organ donation and transplantation are intentionally changed over time. For example, organ procurement organizations are now called donation agencies, and the term organ harvesting became organ procurement, and is now called organ recovery. Cadaveric donors are now called deceased donors. The pattern is always towards a more positive term. I invite readers to read any given term as a synonym and engage in their own substitutions. There are different ways to interpret actions, and by merely changing the word used, the reader gains a sense of the dynamic and politicized character of the field.

Finally, a notable central premise of the study is that donor nephrectomies (kidney removal surgery) are not inconsequential. This is major surgery with the full-spectrum of outcomes, ranging from no long-term impact to death on the operating table. I take the position that even with ideal donor outcomes, having two kidneys is better than having one.

Chapter 2 Scholarly Context, Theory and Methodology

This chapter presents a review of relevant literature followed by the theoretical and methodological approach and data drawn on in the study. I show how the scholarship on body part exchange is dominated by the dichotomous framework of altruism versus markets (gifts versus commodities). This emphasis is grounded in the work of Richard Titmuss in 1970 from which four streams of critical literature have emerged. I categorize subsequent literature as follows: (a) altruism corrupted by the organ shortage; (b) capitalism versus altruism; (c) beyond the binary; and (d) the organizational gift. I identify compelling explanations for observations also made in my dataset throughout and argue at the end, in agreement with other scholars in the ‘beyond the binary’ set, that there is a paucity of research that examines social relations that do not fit the altruism versus markets framework.

The review lays the foundation for situating my intervention which begins with describing the theoretical tools found useful in seeking explanations for the sociological disjuncture identified. This is followed by methodological matters: the design of the study, a detailed list of the data relied upon and how the data was analyzed. This sets the stage for my major contribution theorizing how transplantation works in chapter 3 (which includes a historical account of the development of transplantation). Chapter 4 presents the case of Ontario by detailing who needs kidneys and who provides kidneys to recipients in this place and how deceased donation and living donation are organized.

2.1 Critical Scholarship: The Framework of the Gift and the Market

Transplantation figures as a key topic within a broader field of critical social science scholarship on the place and implications of changes emerging from biomedical technology.³ This field is addressed through the prism of a number of disciplines, such as legal studies, philosophy, sociology, anthropology, and social studies of science and technology. The subject matter of body part exchange, however, is theoretically shaped by a historical framing of the issues that can be attributed to seminal pieces, with deeper lineages from Marcel Mauss, Emile Durkheim, Georg Simmel, and Karl Marx.

Regarded as a classic, is Richard Titmuss's book *The Gift Relationship: from Human Blood to Social Policy* was published in 1970. Titmuss's comparative sociological analysis of national differences in the provision and administration of human blood is credited and critiqued for entrenching the framework of a dichotomy in the characterization and social organization of body part exchanges as either *gifts* or *markets*. To a lesser extent is the work of long-time ethnographers, Renée C. Fox and Judith P. Swazey, who analyzed dialysis and the emergence of transplantation in the United States

³ Many general concerns of meaning and organization that are prominent in the transplant literature are shared with two adjacent bodies of scholarship on biomedicine. First is the field of social studies of science and technology which examines the implications of future and emergent technologies of the life sciences at the cellular level. For example, among others, Paul Rabinow's *Essays on the Anthropology of Reason* (1996) and *French DNA: Trouble in Purgatory* (1999), Gerlach, Hamilton, Sullivan and Waltons' (2011) *Becoming Biosubjects*, and Sara Gibbon and Carlos Novas' (2008) *Biosocialities, genetics and the social sciences: making biologies and identities*. The other relevant set of literature addresses reproductive technology. In the making of babies there are quite obviously significant differences but also similarities in the creation of donors and recipients, as well as surrogates, and mediation of reproduction by physicians at medical clinics and technicians at biobanks. In both sets of research, the role and dictates of economic forms is an important focus of attention. Cellular tissue is often donated as a gift to scientists in labs and housed at private/public biobanks, similarly, reproductive cells are often gifts to women seeking to conceive a child. When and how these body parts—tissues—are commodified is a central focus of analysis. There are a few scholars who jointly analyze tissues and organs in a fashion that blends them together. It is my contention, however, following Steiner (below), that the materiality of the specific body part matters.

in numerous single and coauthored articles and two landmark books, *The Courage to Fail: A Social View of Organ Transplants and Dialysis* (Fox & Swazey, 1974), and *Spare Parts: Organ Replacement in American Society* (Renée C. Fox & Judith P Swazey, 1992). These authors drew on Marcel Mauss's (1967) theory of gift exchange as a tripartite system of giving, receiving and reciprocation. While the gift appears to be a unilateral act of pure generosity, it is an obligation of belonging. Part of membership within a family or group is constituted through the exchange relations of material objects. Titmuss extended this to a view of societal solidarity; Fox and Swazey saw the challenges of gift giving within families. They called the inability of recipients to reciprocate the weighty gift of a kidney the "tyranny of the gift." Below I provide an account of Titmuss's (1970) argument to set the stage for grouping the literature chronologically into several pools that embrace, reinforce, and critique the gifts-and-markets framework for how it works in framing analyses, and for more recent scholars, for what it leaves out.

Titmuss focused on donors in analyzing national systems for the collection and distribution of blood, explicitly contrasting the public model in Britain with the private one in the United States. He provided evidence to support his central claim that altruistic, gift blood systems, relying on unpaid donors, compared favourably to for-profit systems based on paid donation. In the United States, his research is credited with having changed public policy requiring the unpaid, voluntary donation of blood for transfusion, although not for parts of blood that are processed into products.⁴

⁴ This led to a parallel system in the United States whereby whole blood is donated for free to non-profit organizations and plasma, extracted from blood, is sold in a for-profit market.

In the 1980s, as organ transplantation became routinized, deceased donation became organized along the same lines as blood. This is CA: a direct or indirect monopoly by government with a market ban prohibition of body parts traded for money or an equivalent (what is defined in *Gift Act* legislation as “valuable consideration”). Through these parameters, organs, like blood, are defined as gifts that can only be given based on altruism. Titmuss’s work is a touchstone in the field, given its influence on public policy, and, theoretically, by grounding the organization of body parts in the dichotomous conceptual framework of altruism and market, and finding the former superior.

Critics of the neo-liberalist policies of Thatcherite politics in Britain republished Titmuss’s book in 1997 arguing that “in an era of marketised health and welfare services, the arguments of *The Gift Relationship* are even more pertinent than when the book first appeared” (Oakley & Ashton, 1997: 3). Ann Oakley and her coauthors’ use of Titmuss’s work illustrates the political saliency of Titmuss’s claims. They attribute his use of the anthropology of Marcel Mauss and Levi-Strauss to follow a tradition of ethical socialism in British social science scholarship. They promote his book as a counterpoint, promoting the public good under threat “by twenty years of an international liberal market philosophy” (Oakley & Ashton, 1997:3). “The book is ostensibly a comparative study of blood donation in the UK and the USA, but underlying this is a much more general argument about the place of altruism in human affairs,” making “a powerful statement of the liberal-socialist position on welfare provision” and offering a vision of a good society (Oakley & Ashton, 1997: 9). Hagai Boas (2011: 1380) concurs: “the Titmussian vision, in other words, of a welfare regime that provides bodily parts through mechanisms of

generalized altruism, is not just about providing solutions to medical needs but is more about generating mutualism among members of society.”

Thus, for his promoters, Titmuss remains an important defender of the welfare state, with the generation of a supply of blood for medical therapy—and thus organs—argued to be an appropriate extension thereof. There is a right to give, such that government is compelled to provide the opportunity for people to express their inherent altruism by allowing them to give to an unknown stranger for the betterment of the community as a whole. As Oakley and Ashton (1997: 8) pinpoint, blood donation, “like many social, health and welfare services, can be an agency of social integration and an exemplar of community altruism”. Titmuss’s integrative theory and moral philosophy is interpreted in this account to be the view that “a competitive, materialistic, acquisitive society based on hierarchies of power and privilege ignores at its peril the life-giving impulse towards altruism which is needed for welfare in the most fundamental sense” (Oakley & Ashton, 1997: 7). Indeed, many view the altruistic organ and tissue transplant and blood transfusion systems as symbols of solidarity and community. Public policy debate regarding the appropriate scope of the capitalist market relative to the state also continues to resonate, with body parts often positioned as last-stand symbols against a pernicious and expansive commodification.

Following Titmuss’s central intervention, research on organ transplantation has evolved along two paths of critique, the first one expressing concerns of instrumentalism and a second identifying commodification. The link between them is an observed disjuncture between the meaning of the gift and its perceived profanation. There is a perceived threat of increasing utilitarianism and hubris that diminishes the notion of the

gift to rhetoric at best or abandons it altogether. The feared trend is a continual shifting away from pure altruism in the progressive moves away from intra-family live kidney exchanges, to an era of a zealous, industrial-scale bureaucracy that pushes limits within putative altruistic systems, to a complete global market in organs. The first path argues that the normalization and routinization of organ transplantation—within which the organ shortage claim emerged—is detrimental. The second path argues that money corrupts transplantation.

Embedded in various critiques through the trajectory of this literature is a tracing of processes of objectification and commodification—how organs become alienable from embodied persons. As we shall see, the issue of commodification becomes the explicit focus and contemporary scholarship starts to challenge the conceptual framework of a gift/market binary. Finally, in this section of the chapter, I conclude with the work of Philippe Steiner who, more than anyone, brought focused attention to the organizational dimension of organ transplantation.

2.1.1 Altruism: Corrupted by the Organ Shortage

Early and contemporary research on organ transplantation is dominated by medical anthropologists, and the majority of research is located in the United States. Key publications by ethnographers Renée C. Fox (1996) and Judith P. Swazey (1974; 1992), who followed transplantation as participant observers from 1951 and 1968 respectively, set a pathway for understanding organ transplantation. Like Titmuss, it is clear that Fox and Swazey embraced the conceptualization of the organ as a gift and placed great

importance on the social solidarity of organ exchange through *community altruism*. The gift-exchange dimension is what the pair found to be of highest significance to donors and recipients in their ethnographic research, primarily of live donors, over a 20-year period. Fox declared outright that the gift given to strangers epitomizes some of her highest values, of generosity and universalism. Fox and Swazey developed the enduring concept of the ‘tyranny of the gift’ to describe the troublesome emotions of recipients unable to adequately thank their living donor. The inability to reciprocate remains a salient theme in research on organ recipients, reflecting the continued relevance of Maussian gift theory.

What Fox and Swazey found objectionable was a perceived disjuncture – precisely in the way noted in the introduction – between a positive portrayal of transplantation and on-the-ground realities that belied the idea of gifts which by definition cannot be expected and calculated. In a compelling account, they detail what they perceived to be stark juxtaposition exemplified by the introduction of a Donor Awareness Patch by the Boy Scouts of America to induce young boys to talk to their families about organ donation while physicians demonstrated a disturbing utilitarianism and increasing drive towards “limitless attempts to procure and implant organs” (Renée C. Fox & Judith P Swazey, 1992: 204). These attempts include multiple organ transplants, live-donor liver and lung transplants, and expanding eligibility criteria for transplantation to include more diseases.

In our view, the field of organ replacement now epitomizes a very different and powerful tendency in the American health care system and in the value and belief system of our society’s culture: our pervasive reluctance to accept the biological and human condition limits imposed by the aging process to which we are all subject and our ultimate mortality. It seems to us that much of the current replacement endeavors represent an obdurate, publicly theatricalized refusal to accept these limitations (Renée C. Fox & Judith P Swazey, 1992: 204).

Fox and Swazey attributed the hubris they sensed emerging to cultural change; contemporary practice did not reflect the same value system. The significance of organs understood as gifts that they saw playing a large role in shaping transplantation in the experimental era had gone by the wayside. By 1992, supplying organs was not only a justified moral activity but an imperative of nationhood (Renée C. Fox & Judith P Swazey, 1992). The “failure” of inadequate supply fuelled a “missionary-like ardor” among large numbers of health professionals, public leaders and recipients to do more, claiming the “tragic shortage of organs [is] a moral crisis that condemns thousands to die waiting” (Renée C. Fox & Judith P Swazey, 1992: 204; Joralemon, 1995: 342).

Fox and Swazey’s (Renée C. Fox & Judith P Swazey, 1992) book concluded with the pair declaring a public leaving of the field, dismayed by what they saw as a hubris-ridden drive for organs and an increasing utilitarianism—symbolized by the emerging claim of an organ shortage crisis—concealed by a positive portrayal in the public sphere of what was happening. Fox (1996: 267) later responded to a 1993 protocol in Illinois for non-heart-beating cadavers, objecting to the perfusion of organs for the purpose of donation without seeking family consent. She described this as an example of the “seeming willingness to use any means to fulfill its sense of mission about obtaining organs” as originating from “an evangelical attitude toward transplantation, combined with zealotry about procuring organs” (Fox, 1996: 267).

Through the following decade, other scholars joined Fox and Swazey in being troubled by the pattern they identified of emphasis on the positive miracle of transplantation at the expense of its negative sides. Agreement emerged within this

literature that it was the donors who are obscured. For example, medical anthropologist Margaret Lock (1995c: 392) complained that few were aware that “the majority of potential donors are victims of traffic accidents, gunshot wounds, and knifings.” Worse, she notes the potential implications of this paradox: “because a ‘flow’ of organs must be sustained, there is little incentive to work actively against the violence of North American society.” Fox and Swazey (1992) described the determination to procure organs as creating “an almost predatory obliviousness to where the organs come from and how the donors died.”

This set of scholars heavily criticized the organ shortage claim as particularly flawed. For this set of scholars, the organ shortage claim was false and only exacerbated the public-private disjuncture. As Lock (1995c: 392) stated, this is “a self-made ‘organ shortage’.” Her colleague, medical anthropologist Nancy Scheper-Hughes (1998: 14) went further, to say that: “it’s a scarcity that can never under any circumstances be satisfied, for underlying the need is the quintessentially human denial and refusal of death.” Another colleague, Leslie Sharp (2006: 244) identified that the escalation of “organ scarcity anxiety and its consequences” as particularly troubling. A more sociological condemnation was articulated in 1988 by George J. Annas, as one among several paradoxes inherent to organ transplantation.

Shortage problems are also based on the nature of the organ shortage itself, which is largely an arbitrary construct built upon two readily-manipulable variables: patient selection criteria and donor selection criteria...As the success of organ transplantation has increased, the number of hospitals doing transplants has expanded, and so has competition for patients. Older and older, and sicker and sicker patients are now considered ‘suitable’ candidates for kidney, heart and liver transplants. This accounts for another paradox: as the number of organs procured increases, so does the number of individuals on waiting lists. *As long as the total number of transplant programs is uncontrolled, and patient selection criteria are undisciplined,*

there will always be an 'organ shortage'. (Annas, 1988: 621, emphasis added)

Variations of the puzzle Annas pointed to in this passage can be found within transplant literature but are framed as a paradox of success. Unlike others, he suggested both that transplantation is supply—not demand—driven, and, that selection criteria are social constructions.

For the cultural experts, medical anthropologists, it is not transplantation per se that is objectionable but contemporary practices that move away from honouring the sacredness of the gift. The development seen as most problematic is the proposal for a market in organs, in addition to expanding criteria for death and a lack of restraint by transplant programs, exemplified, for example, by exchanging kidneys from youth to grandparents.

As Sharp describes:

Such current realities expose the fact that *the bedrock of an assumed gift economy has already eroded.* A shared clinical and lay commitment to saving and extending lives, at any cost, means that we are quick to accept organ replacement as a legitimate medical right rather than...a strangely wondrous corner of American life (Sharp, 2006: 244, emphasis added).

This interpretation of transplantation implies a conception of gifts as too sacred to be demanded or exchanged without adequate regard for their preciousness. It further implies that transparency and informed decision-making are proper ways of conducting medical and public affairs. The question is how and why has this corruption come about? First, it is notable that this set of authors base their research in the United States. Reasons why organ exchange has transformed in this way range from necessity, to rights, to rhetoric and visibility.

What has gone wrong in Lock's (1995c: 392) view is the assumption that "individuals have a right to receive transplants." The assertion of organ shortage is often indignant, implying a moral wrong and failure of the state. Sociologist Stefan Timmermans (2002) shares this analysis in his research on the confrontation over bodies between coroners and organ procurement organizations. He argues that a similar sense of entitlement to receive organs is found in organ procurement organization language describing coroners as denying saving a life when they assert jurisdiction over a potential donor for criminal investigation. These instances can be interpreted to shift Titmuss's emphasis on the right to give to its opposite in a right to receive.

With respect to rhetoric and visibility, Donald Joralemon (1995) argued that American transplant advocates use the social values of altruism and individual rights as a cultural immunosuppressant to overcome resistance to a view of the body as a collection of replaceable parts available for organ removal for transplantation. In his view, the use of positive values and concepts already familiar is necessary to enable organ exchange. Sharp (2002: 149) took a more political position in an article where she decries what she describes as an ideology of medical democratization for serving as "a potent form of silencing." Again, her research identifies a disjuncture between public issues and invisible aspects of organ exchange. The tenets of this ideology are that all transplant candidates are equally deserving and entitled to equal access, the problem is an insufficient supply of the resource. On this basis, the public is accused of selfishness. Meanwhile, she charges that the lucrative transplant industry avoids scrutiny, American patients lobby for financing to afford transplant surgery along with postoperative immunosuppressant drugs, and the identities

of organ donors is obscured. The last point is especially egregious given the public claims of racial injustice for Latin or African American transplant candidates suffering long wait times while some OPOs rely heavily on urban violence for potential donors, the race and class dimensions of which lie beneath the public radar. For Sharp (2002: 147), stories of murdered young, poor Latino men “are excluded from publicized reports of organ exchange because they involve deeply troubling events too closely linked to the larger realm of urban violence within this country.” Such concealments are evidence of “the larger ideological constraints inherent to the transplant industry” (Sharp, 2002: 145), and reveal how the social worth of individuals is not equal, in spite of the medical democratization rhetoric.

2.1.2 Capitalism Versus Altruism

A second set of authors studying organ transplantation condemns the rise of capitalist exchange relations as an egregious threat to donors and recipients as well as a threat to the altruistic system. While the government of the United States issued a public denial of organ theft and sales rumours, a group of scholars known as the Bellagio Task Force investigated the issue (Leventhal, 1994) (Rothman et al., 1997). Publishing their findings in 1997, the work of the task force set in motion deeper probes that began to reveal concrete evidence and, as addressed in chapter 7, led to a campaign against transplant abuse.

Medical anthropologists Nancy Scheper-Hughes and her colleague Lawrence Cohen established the organization Organs Watch (2000-2005) to document cases, globally, of human rights abuses involving organ transplantation. Scheper-Hughes, in

particular, has been prolific—matched only by transplant nephrologist Francis Delmonico—in championing awareness of transplant abuses through numerous articles on the topic between 1997 and 2007. Scheper-Hughes has analyzed the patterns and contributing factors that enable these practices in various locations around the world theorizing such exchanges and thefts as a sacrificial economy:

These politics, as Scheper-Hughes has noted, raised both old and new concerns about the body as a commodity, as a whole and in parts, about indebtedness and the suddenly mobile pound of flesh, and about organized violence, the persistence of rumor and the ontological insecurity of the poor. (L. Cohen, 2005: 2)

Based on the largest sample of kidney sellers studied to date, Monir Moniruzzaman (2010: 3) theorized the “terrible cost of harm and suffering” to his research participants as a “serious structural violence against the poor.” He specifically dismantled a standard claim, used within the transplant literature, that both recipients and sellers are victims of transplant tourism by demonstrating “how brokers, as well as most recipients, brutally exploit kidney sellers.”

Joining Moniruzzaman is Deborah Budiani-Subari (2009; 2009; 2007), both of whom, like Scheper-Hughes, have sought to give voice to the subaltern.⁵ Their ethnographic evidence contributes to the antitransplant abuse campaign addressed in chapter 7 which includes countering arguments in favour of free or regulated markets in organs (especially as endorsed by bioethicists to) (see for an explicit example, D. Budiani-

⁵ Very few academics have studied the anomalous cases of organ commodification. The exceptions are the work of Diana Tober (2007) on Iran’s legal kidney market and, human rights advocates, Canadians David Matas and David Kilgor (Matas & Kilgour, 2006; Matas & Trey, 2012) on China’s state authoritarian market in prisoner’s organs.

Saberi & Golden, 2009). Collectively, their findings concur: disturbing human rights violations are occurring. The shared basis of opposition is the common anti-commodification position that such trades are founded on and reproduce asymmetrical social relations. Class and intersecting hierarchical social relations of race, gender and citizenship status, as manifest within and across international borders, create the conditions of inequality that enable organ sales. Trevor Harrison (1999: 22) explicitly emphasized that the emergence of a market “must be understood in the broader context of globalization, specifically the extension and intensification of a capitalist mode of exchange.” Others further invoked the argument that the proper role and rules guiding the medical profession are breached, and, so too are the principles of government and democracy to “guarantee the equal value of all human lives” (Scheper-Hughes, 2005: 163). The clear message is that existing inequalities that divide the world into people who matter and others who do not are exacerbated by transplant abuse. Based on his research, Moniruzzaman (2010: 339) identified seven reasons to oppose organ commodification:

1. It constitutes structural violence against the poor.
2. It is seriously harmful to sellers.
3. Sellers’ subjective suffering is far from over afterwards.
4. Deception is widespread in the organ trade.
5. Sellers are manipulated into selling their kidneys.
6. This trade is executed through misinformed consent.
7. It has various negative outcomes.

In the focus on commodification, this literature tends to reinforce Titmuss’s dichotomy by treating altruism and commerce as starkly divided. Altruism, especially through deceased donation is the answer. As we saw in the introduction, in one piece Scheper-Hughes does, however, link the two systems as sharing an imbalance in what the

public hears about deceased donors versus recipients. She posits that the rule within deceased donation in altruism of keeping donors anonymous keeps recipients protected from knowing the human cost of donation and thereby prevents scruples in the recipient population. This is contiguous, cutting across altruism and commercial transplantation. Yet, Scheper-Hughes reserves her criticism for organ markets. Numerous articles of hers have concluded with a long and well-known quote from Titmuss's (1970: 314) *The Gift Relationship* drawing a parallel between his findings and hers:

The commercialism of blood and donor relationships represses the expression of altruism, erodes the sense of community, lowers scientific standards, limits both personal and professional freedoms, sanctions the making of profits in hospitals and clinical laboratories, legalizes hostility between doctor and patient, subjects critical areas of medicine to the laws of the marketplace, places immense social costs on those least able to bear them—the poor, the sick, and the inept—increases the danger of unethical behavior in various sectors of medical science and practice, and results in situations in which proportionately more and more blood is supplied by the poor, the unskilled and the unemployed, Blacks and other low income groups.

Thus, for Scheper-Hughes, altruism is somewhat suspect but still the best option available. She extolled the values attributed to Titmuss's vision: of social solidarity, common humanity, humanism, dignity, and integrity. Moniruzzaman and Budiani-Subari endorsed altruism without hesitation.

Conceptually, then, altruism is both an oppositional and superior way to organize the exchange of organs, even if subject to critique. But, so far, there is a great deal left wanting in the evolution of this research trajectory. Altruism is subject to more critique on its own yet is elevated in comparison. Moreover, is there one altruistic system? There is a tendency to smooth over significant distinctions between deceased and living donation.

The criticisms of altruism as corrupted by its industrial scale and bureaucracy, appears nostalgic: is the answer to try to reclaim the practice of organ transplantation through gift-exchange at its most simple, of cherished giving and gratitude that is the foundation of intimate bonds? How it has come undone is not well articulated. And, when we accept altruism as various and large-scale in organizing organ exchanges, the question becomes what exactly is altruism as a mode of exchange? The literature on capitalism in organ exchange highlights the comparative paucity of research on altruism, and how (if) the two systems are related. Several holes are filled, however, by economic sociologists and more recent social scientists from the disciplines of geography and, again, medical anthropology.

2.1.3 Beyond the Binary

Recent scholars of transplantation articulate a critique of the dichotomous nature of the framework of gifts-and-markets. I found this position very useful to interpreting the data from Ontario drawn on in this study. As I turn to below, the ‘beyond the binary’ challenge made by medical anthropologists shares space with the new commodity theory school dominated by legal and feminist scholars that emerged around the same time (see Ertman & Williams, 2005c). The critique is that gifts and markets are trapped in a conceptual opposition that does not reflect reality. This small body of research argues for an in-between understanding of body part exchange that is less of a sweeping generalization and, as Bronwyn Parry (2008) argues, a more “supple theorizing of entanglements” that stand between what are perceived to be two rigid poles. Part of the emergence of this position is a call for more localized studies to complement or as a criticism of the work of Nancy

Scheper-Hughes. For Cara Keirans (2011) in particular, this critique is a reaction to a parallel good donor/bad recipient dichotomy that she perceives to result from the conceptual binary. Other invisibilities, especially the experience of reciprocity, often serve this subset of literature as empirical cases.

Highlighting medical anthropological strength in cross-cultural comparisons, Crowley-Matoka and Lock (2006) open their research, in keeping with the ‘challenging the dichotomy’ approach, with the provocative story of two geographically distant transplant centres leading a family in two different directions. In Mexico, living donation is encouraged. Here living donation is viewed as a normal sacrifice that extends the caregiving role of motherhood but also emerges as a result of poor access to deceased donor organs. In Germany, deceased donation is encouraged. Here medical teams are more hesitant about the risk of harm to living persons. Along these lines, they analyze significant differences in character and implications of organ transplant exchanges in five countries: Mexico, India, the United States, Spain, and Japan. Who donates and the terms of donation vary significantly. Such work serves to pluralize and complicate altruism as well as markets by raising the profile of the “in-between” cases; for example, in Mexico there are tangible returns offered in exchange for a kidney among kin. Valuable items are both used as enticement and considered “simple fair-minded reciprocity” (Crowley-Matoka & Lock, 2006: 178). Spain, Japan, and the United States are different again. These cases demonstrate “the multiple and fluid nature of the possibilities for bodily commodification in transplantation” (Crowley-Matoka & Lock, 2006: 178).

The logic behind who donates in live donor-recipient relationships is also revealed to be complex. For example, in Mexico, live donation by mothers is less for love than “to safeguard the economic survival of the family as a whole,” in a gendered economy where formal sector jobs are disproportionately held by men (Crowley-Matoka & Lock, 2006: 178). Cohen (2005) also found gendered dynamics at play in India. In this location, having had a previous operation, such as a hysterectomy following a hospital birth, made women more operable. Using Cohen’s words, women’s dependence on male breadwinners or previous surgical encounters rendered female bodies more bioavailable.

This work advances the field by setting a research agenda of identifying what is at stake and how boundary-pushing occurs. Building on this approach, Parry (2008) explicitly issued a rebuke of the dominant dichotomous conceptual framework:

Richard Titmuss’s now paradigmatic, but primarily oppositional, model of “gifting” and “commodification” has provided perhaps the most potent organising principle for conceptualising transactions of tissues and organs in contemporary Western societies. In this paper I have argued that this model is *insufficient* to take account of the multiply constituted and complex transactional behaviours evident in the organisation and operation of a new globally extensive market for human bodily parts and tissues...[and] our complex, negotiated relations to them (Parry, 2008: 1143)

Her primary research and evidence is of the circulation of cellular tissues. Parry’s work, like Crowley-Matoka and Lock’s, is valuable in identifying how the paradigm of gift and market “seeks to establish a clear, patrolable boundary between what it perceives to be two distinct sets of transactional behaviours” (Parry, 2008: 1143). But such a boundary can become a fallacy in practice. Parry implies that the dichotomy was an imposition on tissue holders that concealed a more honest accounting of what was happening. Tissues were exchanged for various types of valuable “commodities” such as co-authorship on an

academic article or research licences. In my view, the same argument can be applied to the partial or quasi commodification status that kidneys and partial livers hold when donors are compensated for their inconvenience. Both instances use the terminology of “compensatory fees” instead of “a price charged to secure the resource or commodity” (Parry, 2008: 1134). The inability of tissue holders to call their possessions either gifts or commodities “speaks eloquently of the need to begin the task of finding more supple ways of characterising these transactions that break down, or at least complicate, the binary distinctions that have dominated such analyses to date” (Parry, 2008: 1134). Following this line of argument and drawing on research on organ sellers (as reviewed above), Parry also attacks the pro-regulated organ market position by insisting that, “to appeal to money—that apparently homogenous, universal currency—to regulate such complex transactions suggest its ability to *commensurate*, what are, in effect profoundly differentiated experiences of bodily commodification” (Parry, 2008: 1143).

Cara Kierans (2011: 1470) similarly called for a re-conceptualization, arguing “that attention should turn to the ways in which particular practices of giving and receiving give rise to the relations that underpin commodification and gift-giving.” She issued her criticism specifically at Scheper-Hughes whom she accused of employing “overly determined frameworks”:

In the attempt to deliver a unified, ethnographic counter-narrative to dominant biomedical discourses around organ transplantation, the problem is that analyses of this sort become the mirror-image of the discourses they are designed to critique. Rather than abandoning one-sided accounts, they set up yet another simplifying opposition, i.e. donors good, recipients bad. It is because of this that market analogies and commodity discourses, while frequently penetrating, begin to fail us at important junctures... We need to look to the ways in which distinctions are continuously redrawn, blurred

and elided in the course of the everyday practices of organ transfer in particular settings. (Kierans, 2011: 1473)

The polemic of the conceptual binary is disrupted by research findings, like Crowley-Matoka's (2005), that reciprocity—especially coping with immunosuppression—is also rendered invisible in public knowledge of organ donation. Like Cohen (2005), Kierans turns to social science uses of immunology as articulated by the work of Donna Haraway (1991) to resituate these relationships balancing donor and recipient experiences.

This set of authors therefore call for empirical analyses of how body commodification—and suffering—is constituted in different contexts, across processes of organ transplantation. Parry (2008) wants greater honesty, asking “Why aren't these transactions called markets?” Like Steiner (below), Parry pointed to a legal and sociological divide: what is not legally permissible to be a commodity is just that, in sociological terms. What then, she asks, is a commodity?⁶ To answer this question, Parry took up what is known as the commodification debate, drawing first on Arjun Appadurai's (1986) well-known conceptualization that commodities are not fixed but rather move into and out of the state of commodity candidacy. Similarly, Parry agreed with legal scholar Margaret Radin's idea of partial or unstable forms of commodification. There is no threshold moment when gifts “cross an invisible ontological divide, becoming in that moment ‘commodities’” (Parry, 2008: 1135). The task, then, is to identify when and how such conversion occurs.

⁶ Notably, in asking what it means to say that body parts may not be “transacted for profit,” Parry's line of inquiry mirrors that of promarket advocates challenging the ban against “valuable consideration” in the exchange of organs for transplant.

Parry began, then, to invoke the “beyond the binary” critique spearheaded by feminist and legal scholars of the new commodification school. Martha M. Ertman and Joan C. Williams’ collection (2005c) captured the shift from canonical texts by Richard Titmuss and Arjun Appadurai to contemporary theorists of this school who reject the basic premises of the classic commodification debate. At stake is a boundary issue, asking what is and ought to be for sale that is traditionally characterized by an on/off question of whether or not to commodify. The assumption which is shared by both market enthusiasts and anti-commodification sides of the debate is a conceptual framework of “hostile worlds,” described as the view that,

...the world is bifurcated into an economic arena dominated by rational self-interest and self-interest alone (the market), and a sharply different arena of intimacy and altruism that must be protected from the kind of instrumental behavior that is appropriate in market contexts. (Ertman & Williams, 2005a: 4).

Evidence is shored up to show that the boundary lines between a public, economic world and private, intimate world are blurry rather than clear. In giving up “the Hamlet question” of to commodify or not, these scholars seek to uncover what lies beneath: “the traditional debate deflects attention away from more useful inquiries into the interactions between marketization proposals and the distribution of social power” (Ertman & Williams, 2005a: 5).

2.1.4 Philippe Steiner: “The Organizational Gift”

Another approach to understanding organ transplantation is offered in the work of economic sociologist Philippe Steiner (2003, 2006, 2008 [2006], 2009), in somewhat

similar ways to his subdisciplinary colleague, Keiran Healy. Both focus on altruistic regimes and address the commodification debate but draw attention to the industrial and organizational aspects of these exchanges, in other words, the necessary parties that stand in-between donor and recipient. Steiner's analyses drew on the work of classical theorists Marcel Mauss, Emile Durkheim and Karl Polanyi as well as (like Healy) contemporary theorist Viviana Zelizer (whose work follows that of Georg Simmel).

Steiner (2008 [2006], 2014) tackled the theoretical quandaries of what a human organ as a gift is, exactly, and how the movement of body parts is organized in altruistic regimes (and elsewhere) through conceptual and theoretical analyses. He saw deceased organ donation as a manifestation of Durkheim's organic gift and argued that deceased donation was a "death-impelled solidarity" (actual death or the threat of death). His work developing conceptual models of different pathways organs and tissues follow fits well with the separate spheres critique in focusing on the actors in-between donor and recipient. Where Parry (2008), above, pointed to the actions of individual scientists in possession of human tissues shifting these objects in and out of a commodity state (loosening their personal ties and psychic connections with each iteration), Steiner's analysis takes a structural view. He argues:

When the donation process gets distended, either in that the number of intermediaries increases or new phases increase the length of time between the beginning and end of the chain . . . that process becomes more permeable to economic relations while *sensitivity* to the economic relation weakens. (Steiner, 2008 [2006]:138)

Steiner's comprehensive 2006 typology of the forms organ and tissue exchanges take identified four dimensions in its classification scheme. He claims that these features shape

the character of giving: the materiality of the body part; time (whether exchange can be deferred or must be immediate); the length of chains of actors between donor and recipient/consumer; and, relatedly, the use of money. Tissue is commodified more easily than organs because of differences in the materiality of the body part, which contributes to its preservability, which in turn distends the chain and becomes open to market relations. Organ donation is divided into two polarized forms: *post mortem* and *inter vivos*, which differ on the five bases: legitimacy (consent versus motivation), quantity (multiple parts versus single), organization (unplanned with tight time constraints versus planned), solidarity (*societal donation* and a *family solidarity donation*), and donor-recipient relations (anonymity versus a strong family tie).⁷ In keeping with Titmuss's conception of altruistic blood systems, Steiner (2008 [2006]: 135) argues that deceased donation "is an abstract gift made to an abstract community." *Inter vivos* donation is closer, in his interpretation, to Mauss's classic figure of the gift given that, "the two ends of the giving chain know each other and are related to each other" (Steiner, 2008 [2006]: 135). Steiner also categorizes three types of organ markets: (a) the spot market of personal, direct cash exchange between live donor and recipient; (b) the black market of indirect monetary exchange between a live donor and recipient facilitated by a broker; and (c) the pseudo market of deceased donation proposals involving insurance schemes before death.

⁷ Indeed, deceased and living donation are reflected in a deep divide within transplant literature and contribute significantly to the isolated approach of social scientists engaging in empirical research. To my knowledge, this study is unique in including both deceased and living donation.

The value of this typology is as a hermeneutic tool, enabling further analysis of each type as well as immediate and diachronic comparison. As we see in Chapter 8, developments since 2006 have already rendered some of Steiner's distinctions and categories obsolete and others even more prominent. His overarching point is nonetheless to clearly grasp the organizational nature of organ donation. This form of transaction between people necessarily entails intermediary organizations and institutions; in the Durkheimian tradition followed by Mauss, "the sense of who is present, who does what and when they do it, etc.—is crucial" (Steiner, 2008 [2006] :146). Thus, it is what the in-between parties are doing that matters. "In this sense we can say that organ donation is embedded in an organizational or institutional context...in much the same way as economic sociologists understand the market to be embedded" (Steiner, 2008 [2006] :146).

Steiner's approach to the commodification debate is to juxtapose the ideas of Viviana Zelizer and Karl Polanyi, asking, "who is right about the modern economy?" Zelizer is well known for her extensive research on the meanings of money. She counters commodification anxiety by showing the multiple forms and meanings attributed to the use of money. Culture is modified by commodification but the Zelizer view is that money is modified by culture. Steiner's interpretation is of a "money society symmetry" in her work which poses a challenge to the Polanyian view that the market poses a danger to society (Steiner, 2009: 101). He explicates the contrasting concepts of freedom that inform each theorist, Zelizer, the liberal view of non-intervention, and Polanyi, the Republican or neo-Roman view of non-denomination.

With respect to organ transplantation, the liberal view is that the market is the ultimate solution for generating the quantity of organs required and, from Zelizer, “making the cultural dimension fit into this new commodity through appropriate rhetoric is only a matter of time” (Steiner, 2009: 105). The Polanyian view is to condemn the creation of a market for the “fictitious commodity” of organs as a “nightmarish” step into a world of total commodification (Steiner, 2003). But Steiner points to a third possibility that breaks the gift versus market deadlock in the “creation of carefully designed pseudo-markets or pseudo-gifts.” For example, a contingent future market in which a monetary reward is given to charitable organizations through bequest, or what is now known as kidney-swaps or trades (officially list-paired or paired exchange) among incompatible donor-recipient dyads. Steiner envisions that “political debate would play an important part” in advancing these intermediate solutions. Especially in identifying “what people could tolerate in respect of the tension between conflicting values in the context of tragic choice and strong repugnance to markets” (Steiner, 2009: 105). How the emergence of pseudo-gifts unfolds in Ontario, addressed in Chapter 8, advances Steiner’s theorizing. In Ontario, there is a careful use of words and no strong reactions to several living donor innovations. As such, I argue that these changes bend rather than challenge existing organ exchange relations.

In his most recent work, Steiner (2014) expands upon his conception of “the organizational gift,” which he defines as “an ‘arms-length gift’ or a ‘gift at distance’ compared to the direct gift theorized by Mauss.” Organs are genuine gifts but of a specific type. The presence of organization(s) modify the Maussian gift in two ways: there are two types of actors—individuals and organizations; and, non-gift relations exist between

organizations. The gift between primary parties, of donor and recipient is intercepted therefore by the character of other relations such as asymmetry between individual and organizational actors. Steiner (2014: 12) calls attention to the distinction between, and combination of, interpersonal connections between live donors and recipients, and, impersonal interactions with professionals.

Steiner also raises three issues important to appreciating the organizational gift that open up new pathways for empirical investigation. First, the influence within and across organizations of tariffs and costs to pay for the high price of transplantation. Second, power relations and control issues shaped by “organizational scripts” and organizational interests. For example the exercise of symbolic power by physicians, and transplant centre claims to organs for their patients. Third, as he argued earlier, is the length of relational chains. As in his 2006 typology, Steiner insists that differences arise when chains are longer, for example, by distancing donor from recipient to the point of permanent (or temporary) strangers.⁸ Where market exchange occurs between organizational actors that stand in-between donors and recipients, the boundaries separating the spheres of market exchange and personal relationships blur. Studying organizations is critical as this “may render the negotiation more difficult” or “offer the possibility of going beyond face-to-face relations, and link the cultural shaping of transactions at the micro-level to political decisions and

⁸ In some cases, donor-recipient strangers later come to know one another. For example, this study included a recipient who met and befriended her deceased donor’s family. Another example is of non-directed live kidney donors and recipients who meet afterwards as “kidney kin.”

political debates at the macro-level” (Steiner, 2014: 12). Cultural meanings are often more stable, accepted and taken for granted through the presence of organizations.

2.1.5 Gaps in the Literature

This review has identified four sets of literature relevant to this study, each with their own critique of how organ exchange is practised and/or theorized. To summarize, the first set has the longest history, embracing altruism as a superior way to organize and manage the exchange of body parts yet critiquing how it is practised by intermediaries as calculating, obfuscating and misleading. The second set focuses on existing (and, to a lesser extent, proposed) organ exchanges that are capitalist, as well as authoritarian in China, and in some cases involve theft. Here the contrast between altruism and capitalism is heightened with the former exalted in spite of one suggestion of linkages between the two, in Scheper-Hughes’ critique of donor invisibility and a shared framework of organ shortage. The third set of literature claims the dichotomy of altruism-capitalism is no longer valid; rather than “separate spheres,” the two modes of exchange are “entangled” but a better conceptual framework has yet to emerge. A fourth set of literature hones in on the organizational dimension of organ exchange. Taken together, these streams of literature lay a rich groundwork for understanding organ exchange. Nevertheless, these accounts fail to adequately explain the case of kidney exchange in Ontario.

Thus, the theoretical picture painted by this literature is only partially filled in. On the one hand are questions about altruism suggesting trouble that leaves vast room for further analyses. For example, research to date focuses on the reciprocity dimension of

gifts yet critiques of altruism point to aspects of organ donation media campaigns as problematic in concealing reality. Where and how does the “asking” part of gift-giving fit analytically? On the other hand, many more scholars have tended to leave altruism alone, focusing on tracing commodification, but clearly the two are interrelated, somehow. There is room for more research on altruism in and of itself and in relation to other modes of exchange. And, exactly how organ exchange works – especially where kidneys are gifts and not commodities – remains unarticulated. Below I turn to an identification of the theoretical approaches I found useful in interpreting my data. This is followed in the third section by an account of my methodological approach and a description of my data.

2.2 Theoretical Tools

What I found helpful to explaining what enables and inhibits kidney exchange in Ontario, taking into account the disjuncture observed, are three theoretical approaches which I organize as: 1) the process approach within commodification theory, and the idea of rules and boundaries as conceptual tools; 2) theories of knowledge as dominant and directed; and, 3) critiques of altruism. In conjunction with the scholarly work reviewed above, the first two bodies of theory are drawn on in the next chapter where I articulate my account of how organ exchange works. Chapter 3 is thus motivated by the need I found to establish a vocabulary and some concepts to account for my findings regarding the complexity of transplantation, especially how kidneys become “medicine,” through an imbalanced tension between donors and recipients, mediated and influenced by intermediaries. Theories of altruism are used in chapters 5 and 6 to hypothesize

explanations for the formation of dominant knowledge that deflects attention from the complexity and limits to alienability in deceased donation.

My approach overall takes a critical realist view that the practice of medicine and its scientific foundations are not free of social – including political – decisions. The key ‘social’ decision legitimizing the alienability of kidneys in deceased donation is captured succinctly by Margaret Lock (1996c, 2002). She describes what the Japanese did not accept from 1967 to 1999, that was accepted in the West: that death was a measurable point in time that is “scientifically deducible and verifiable” (Lock, 1996c: 577). Death in Canada, United States, Europe and many other countries was, by contrast, subject only to scientific forms of authenticity, not invoking ontological questions that might stand in the way of donation. In living donation, variation in donor eligibility criteria across different transplant centres affirm that this form of kidney exchange also entails social decisions.

My study also found grounds to respond to the call by new commodity theorists for analyses “beyond the binary” of the dominant gift versus market framework. As we shall see, the gift-market conceptual framework is not irrelevant in Ontario. It is active and works in the way Titmuss conceived, as described above. In chapter 8 we see that suspicious living donor kidney exchanges at transplant centres in Ontario are turned down. But the role this dominant framework plays at the policy level is less straightforward. On the one hand, the comparison elevates altruism and contributes to a disincentive to disclose information that might deflate that status. At the same time, for a range of reasons explored in chapters 5 and 6, the blame laid on altruism for a low deceased donation rate serves to justify occasional calls for its abandonment in favour of some form of monetary exchange.

Notwithstanding the relevance and significance of the place and pushing of the boundary that marks the distinction between gifts and markets, the research conducted for this study found something else at stake – the alienability of kidneys. And, as the new commodity theorists suggest, my research found important forms of social power – regarding alienability (meaning the legitimacy of kidney removal within an altruistic mode of exchange) – at play beyond, although entangled with, the dominant gift-market debate.

2.2.1 Processes of Objectification: Theories of ‘Things’

As detailed in the review above, literature on organ transplantation adopts the standard in/alienability distinction in reference to the use of money and this is, of course, at the core of commodification literature. Using money as the distinguishing variables leaves a missing piece when the ‘thing’ in question is a human organ. Kidneys are not independent ‘things’ until surgically removed. To understand how kidneys are exchanged, I needed an account of exchange that included not only how an existing object shifts to and from commodity status but how kidneys become objects in the first place. There are three statuses of ‘thing’ in Ontario: the kidney as too precious/vital to be exchangeable; a quasi-thing, called an object or gift available for conditional exchange; and a commodity bought and sold. Thus, in my account inalienable refers to the first status that a kidney may not be removed, and alienable refers to the latter two statuses of object/gift and commodity.

Few scholars conceptualize the process of transplantation, the notable exceptions are Lawrence Cohen’s (2005) account of who becomes ‘bioavailable’ (in chapter 4) and Steiner’s attention to intermediaries (above). However, their models did not sufficiently

capture my findings in Ontario. What I found helpful to developing my own account (in the next chapter) was the literature on commoditization as a process. Igor Kopytoff's (1986) essay, "The cultural biography of things: commoditization as process," and, to a lesser extent, Arjun Appadurai's (1986) essay in the same collection "Commodities and the Politics of Value" fit this description. For this school of thought, which many anthropologists have drawn on, commodities are not fixed but rather dynamic 'things' that move in and out of commodity status. Understanding when and how one or another status holds requires examining "a process of social transformation" (Kopytoff, 1986: 65). This entails following the cultural biography of a particular thing through processes of commoditization:

In doing a biography of a thing, one would ask questions similar to those one asks about people: What sociologically, are the biographical possibilities inherent in its "status" and in the period and culture, and how are these possibilities realized? Where does the thing come from and who made it?... (Kopytoff, 1986: 66)

I found that by replacing commodification with objectification I could draw on this approach to discern how kidneys become separated from persons in the process of kidney donation in Ontario's altruistic regime. This is demonstrated in the ensuing chapter. Notably, my adaptation of this approach primarily considers these questions from an organizational standpoint, at the mezzo-level of analysis (rather than the micro-level), and draws out the societal (macro-level) challenges and implications. As we see in the next chapter, I ground my account on an interpretation of the historical establishment of transplantation as a legitimate therapeutic modality. Here we see what Kopytoff and Appadurai emphasize, that what undergirds visible transactions is a moral economy that

culturally marks some things as being available for exchange and others not. In this case, kidneys within altruism are conditionally available, as gifts.

Understanding what the creation of kidneys as things requires, in my view, examining both the relationality of donors to recipients (through intermediaries) and the demarcations that enable and inhibit kidney exchange. For this task I found the conceptual tools developed regarding categorical constructs/classification and boundary-work to be helpful. Geoffrey C. Bowker and Susan Leigh Star (1999) are best known for their work on classification. They argue that classification systems and standards constitute an infrastructure that plays a fundamental role in shaping our society. This is the scaffolding that organizes our behaviour, decisions and how we live our lives. Such systems and standards are so essential they often become invisible and thereby escape critical examination. Bowker and Stars' project is to expose classification schemes as social constructions. Their focus on classifications complements the work of Ian Hacking (1986) whose historical analysis of social construction I drew upon in my previous research.

Classification schemes like all social constructions erect demarcations to separate some things from other things. This allows categories to become visible from which action becomes possible. Tracing the establishment of boundaries has therefore become a standard analytical tool for sociologists. Lamont and Molnar (2002: 169) argue that boundaries "point to fundamental relational processes at work across a wide range of social phenomena, institutions, and locations." Who and how boundaries are set and the role they play involves the assertion of power.

In the literature reviewed above, scholars in this field employ the concept of boundaries in several places. Transplantation invokes the construction of boundaries in setting eligibility criteria that put patients with End Stage Kidney Disease on or off transplant waiting lists and accept or reject potential donors. And, transplantation is interpreted to invoke the crossing of boundaries, for example between life and death, self and other, and, animal and human, creating liminal spaces and hybrids. Of the many that abound in this field, the boundaries I focus on are those that divide to enable or inhibit exchange. For example, I claim that ‘seeing’ potential recipients enables transplantation, as does the practice of individuals constituting themselves as potential, and actual, donors.

The other focus is on how boundaries are drawn and by whom. This brings us to the last key theoretical source, the critique of the epistemological divide between the ‘social’ and ‘science’. Bruno Latour’s (1993) book, “We have never been modern,” is what I drew upon in my previous research to analyze the forms of authority invoked to defend the claim that brain death is death. This is useful again to discerning the same modes of reason and domains of authority that hold sway in processes of objectification that carve out what is officially considered legitimate (even if it is contested) and what is not legitimate. For Latour, science is politics by other means. In place of adopting the cultural practice privileging science as a distinct field with special access to truth, he advocates researchers view all forms of knowledge as integrated and observe the effect of the division in Western society between science and the social which he calls the ‘Great Divide’. It is not enough to accept science and look for social influences and biases upon it.

2.2.2 Knowledge as Dominant and Directional

A central concept I develop to explain my findings is recipient-centrism. In the next chapter, I detail the process through which I arrived at this concept by building upon a concept I created and used in passing in my previous work – a ‘double-gaze’. The purpose of the conceptual development is to provide a language with which to describe an orientation and degrees of thinking and acting in the interests of recipients as opposed to donors. My claim that there is a need for such a language accepts and builds upon the scholarship on organ transplantation (reviewed above) by agreeing that there is a tension between the interests of donors, recipients and intermediaries, and, second, on my findings which affirmed the phenomenon of a ‘structured forgetting’ of donors in Ontario. Here I explain the theoretical origins of the concept of a ‘double-gaze’ and recipient-centrism’.

The concept of a gaze is part and parcel of social theories of domination through orientations in thinking and knowing. The gaze is a visual theory that extends the idea of social orders as structured by “centring” what is in the best interest of the dominant party. Scholars of visual material, from paintings to film and advertising, developed various types of gazes to articulate how an audience views what is presented to them generally categorized by who is doing the looking. For example, the feminist concept of a male gaze is used to identify images produced by and for heterosexual men that objectify women and thereby affirm male power over women (Mulvey, 1975). Notably, for the party objectified, women in this case, receiving the male gaze is constituted as desirable. In this way, women come to objectify themselves to conform to the male gaze. Receiving affirmation of

objectification comes to replace subjective agency, or, becomes a form of exercising agency sometimes labelled “false-consciousness.”

Other types of gazes and centring of knowledge, such as racialization and Edward Said’s (1978) orientalism, follow the same idea as the male gaze. For feminism, and even more so racialization and orientalism, there is more agreement about the first act of gazing and structuring knowledge to serve the dominant party than in how those objectified receive and respond to this treatment. How agency is exercised by people subjected to forms of domination is a large subject of debate that generally positions self-objectification and resistance as two poles along a continuum of possibilities. The point here is that my concepts borrow directly from these theories of domination to add another type of directed knowledge specific to the therapeutic modality of transplantation. A key difference, addressed below, is that altruism is a virtue.

2.2.3 Thinking Through Organized Altruism

How can theories of gazes and domination apply to altruism where there is no oppression, only positive action towards another—precisely the opposite of the kinds of behaviour and thinking that these theories decry? Of the many questions that might be asked, the broad question is: what is organized altruism and how does it work as a mode of exchange?

In terms of ideology, altruism is a concept of social psychology that has retained a focus on individual action.⁹ It is defined as follows:

⁹ It is claimed to originate in the work of August Comte.

Behavior that not only provides benefits to its recipient but also provides no benefits to the actor and even incurs some costs. If one conceives of psychological rewards as benefits to the actor, this definition of altruism is so narrow that it excludes virtually all human behaviour. Hence, many social psychologists maintain simply that altruistic behavior need exclude only the receipt of material benefits by the actor (Howard & Piliavin, 2001: 114).

Through intimate relationships between individuals and as community-based organized giving, altruism is other-directed: the behaviour of giving is undertaken for the benefit of others. And, it is idealized as a “pure” transfer, free of reward, but in practice is a form of exchange with the only return being psychological. Of several subordinate questions regarding how organized altruism works, the one corresponding to my focus on the front-end of organ exchange is: may potential recipients in need of gifts solicit them? In other words, may gifts be asked for and if so, by whom and how? What makes asking fair and moral? And how does this work within the two types of altruism, one community-based and the other among intimates?

I draw on three sources to advance our thinking about organized altruism. Naomi N. Duke (2013) and L. Song Richardson (2013) addressed cases of altruism in scientific research studies involving human subjects and analyze forms of power attendant to altruism. Both identify ways altruism is invoked in the evasion of accountability. Duke’s (2013) case is historical, critiquing the portrayal of participants’ involvement in medical research as voluntary and benevolent acts of altruism. She demonstrates how such claims not only distort but exacerbate the original violation of compelled participation by low-income, racialized patients whose role in the research fails entirely in meeting contemporary standards of informed consent to participation.

Richardson (2013) explores what she called an *idealization bias* of social status, and a *social benefits bias* as two possible explanations to account for the lack of criminal accountability of human subject experimentation in spite of clear, documented cases of violations by researchers. Her identification of social benefit bias contributing to an implicit immunity may be specifically relevant to the case of altruism in organ transplantation. For example, it is eerily reminiscent of separate findings, mentioned above by Scheper-Hughes and by Timmermans, that the good to all of saving a life in the context of organ scarcity trumps raising other concerns. Indeed, as we see in the chapters that follow, acts deemed to contribute to the common good hold a special social status and this in itself is a form of power.

The other helpful theoretical work is by Jacques Godbout with Alain Caillé in *The World of the Gift* (1998). They offer a conceptual framework of four sectors: the private world of the (traditional) gift, the market, the state, and a sector where the modern gift circulates as the gift between strangers. Each of their four sectors is a system of exchange that operates based on distinctive logic, principles, and meaning. The distinctions draw on Albert Hirschman's (1970) concepts of loyalty, exit and voice.

The gift exchange world is characterized by loyalty as long-term relationships are formed and maintained; the market world is characterized by exit as parties are not obliged to anything more than a self-interested and calculated transaction; the state is characterized by voice through entitlements within democracy. The fourth world of "unilateral gifts to strangers," such as organs, resists "the utilitarian practice of calculating 'pluses' and 'minuses'" (Godbout & Caillé, 1998: 94) and exists somewhere in-between the other

worlds, especially the state and private gift sphere.¹⁰ But, given that they function according to different principles, Godbout and Caillé argue that gifts and the state can clash. In universalizing the circulation of goods and services, the state creates a bond between strangers, links all individuals to bureaucrats as intermediaries, and its services are rights-based. My argument at the macro-level, using Godbout and Caillé's use of Hirschman, is that the "loyalty" required by altruism stifles the "voice" required by democracy. In other words, that the loyalty that arises in the gift sphere contributes to compromising other social values and expectations of the state, namely transparency and accountability which are critical to democratic decision-making.

To draw from Godbout and Caillé (1998: 61) a bit further, these scholars are in agreement with Philippe Steiner (see above) in recognising that the mediation of the gift contributes to voluntary organ exchange not being "...the 'pure' system of the gift, for these intermediaries—technicians and professionals—are governed not by the gift but by a salaried relationship". The friction between 'worlds' speaks to my finding of a supply pressure—donor protection tension. The state is rights-based and utilitarian in 'producing' organs from deceased donors yet they are constrained by families who own organs as 'gifts' and conceal a means-end drive by using gift rhetoric in their exhortation. Workers must sacralize organs as gifts and yet maximize numbers. In live donation, organ donor coordinators in Ontario, the altruistic brokers, mediate the spontaneous gift, as Godbout

¹⁰ Here individuals are motivated to give their time, money or body part as a moral act that follows the spirit of the gift but gifts are given to people unknown. As a result, these social relations do not fit the three part cycle of the gift; gifts are received but there is no reciprocation. There may be psychological benefits but there is no tangible return. This category includes and is most straightforward for mutual-aid, self-help groups and volunteer work for a charity.

and Caillé describe it, by playing the role of rational decision-makers. In some senses they appear to be more protective of donors than the potential donors. In another light, transplant centres have their own motivation for approving donors in that they must maintain a minimal level of surgical volume to keep their doors open.

2.2.3 Democracy

Last, I turn to an underlying measuring stick that runs through the thesis—of democracy. Richard Titmuss (1970: 11) used five criteria in his study of blood systems: social value, cost efficiency, biological efficacy, safety and purity. His focus was on “the morality of society” and humanity’s “regard or disregard for the needs of others.” Today, in the aftermath of the contaminated blood scandal, the legitimacy of the Canadian blood system continues to rest on safety (A. Smith, Fiddler, Walby, & Hier, 2011). Meanwhile, the dominant measuring stick for evaluating organ donation and transplantation systems is the volume of supply. Although I agree that the more organs provided altruistically the better, my view is that this single variable is too narrow a measuring stick for evaluating the way in which organ exchange occurs in Ontario. It precludes other values and possible costs of exchange.

This study therefore embraces Titmuss’ notion of social value but claims there is more than one social value. What I add are two preconditions for democratic, public decision-making: transparency and accountability. Identifying democracy as an additional social value is based on the view that determinations which fall under the authority of medicine are social decisions. This position embraces the viewpoint articulated in 1988 by

two observers of transplantation, George Annas and John Lachs. The quote above (in section 1.1) by Annas (1988) regarding the paradoxes of deceased donation argued that the organ shortage was a social construction – more specifically an arbitrary construct based on two sets of eligibility criteria, one for transplant patients and the other for donors. Lachs (1988: 237, 239) put forward a similar critique in response to debates in the United States regarding brain death:

What we are doing in declaring death is marking a point along the continuum of organic decline which involves a social choice...Where we put it is a matter of choice determined by the beliefs, values, and circumstances of the community...The naiveté of the realistic view...succeeds only in keeping the choice unconscious and hence uncriticised. The thought that we can discover the point of death conceals from us what we really do and thereby makes an intelligent examination of our activity impossible.

Both scholars value exposing social choices and Lachs, in particular, identifies transparency as a necessary first step for examining those choices. The lack of evidence identified by sociologists Healy and Nowenstein in the introduction serves as a small insight on a larger phenomenon signalling that the means to the end within altruism may not live up to Lachs' standard. On this basis, what is of specific interest in this study are the requirements of democracy, specifically, the elements of transparency, accountability and evidence to inform public policy decisions that aim to improve the health of all members of society.

2.3 Methodology: An In-depth Case Study of Kidney Exchange in Ontario

Several major influences contributed to decisions in the design of the research. First was the aim to better understand altruism without excluding Ontarians' participation in other

modes of exchange outside Canada. Second was to take a ‘broad and narrow’ approach that included deceased and living donation. Third, one organ was chosen to contain the important differences that distinguish organs and tissues from one another in transplantation. Thus, the design of the project is a representative case study that focuses on the macro-scale and mezzo-scale influences on organ exchange. Sources of data and methodology are explained in what follows.

This project covers the time period of 2000 to 2014, following my previous research on deceased donation in Canada from 1967 to 1999. To ground my analysis of the social relations of organ exchange, I examine one jurisdiction and focus on one organ, the kidney, as used through the therapeutic modality of transplantation to treat patients with End-Stage Renal Disease (ESRD)(also known as End-Stage Kidney Disease). This decision agrees with geographer Gail Davies’s (2006: 257) claim: “it is only through tracing the intersection of ethical, corporeal and technological practices *in situ* that we can fully reflect on questions of justice within the developing bioeconomy.” Containing the analysis to a specific (albeit mobile) population within one jurisdiction allows for an analysis of how the movement of kidneys is enabled within and across one space.

The kidney is selected for a number of reasons. It has the longest history in transplant medicine with changes in practice over time, especially in relation to the other way to sustain End-Stage Renal Disease patients using dialysis. A longer history provides earlier data (in Canada from 1981). Kidneys rank highest in demand worldwide. Although categorized as a vital organ, the kidney is a paired organ one of which can be removed without causing death. As such, there are several different terms by which kidneys are

being acquired around the world, among them: from living and deceased donors; within families, from friends, acquaintances and now strangers on a non-remunerative basis, and, for cash through profit-making brokers. This variability by donor type, over time and by place makes the kidney a good candidate for a study of rules governing the movement of organs.

Notably, different levels of analysis play a significant role in this project. Table 1 below aims to clarify the scheme I follow in referring to macro-level, mezzo-level and micro-levels as they bear influence on how deceased donation and live donation are enacted in Ontario.

Table 1

Levels of Influence on Deceased and Live Donation

Categorical Level	Scale	Example
Macro-level	Supranational	International Medical guidelines
	National	Canadian Council for Donation and Transplantation
	Provincial	Government of Ontario, Public discourse
Mezzo-level	Institutional	OPOs and transplant centres
Micro-level	Individual	Donors and recipients

2.3.1 Data Sources

All data analyzed are textual, statistical and based on interviews with key informants. All sources are listed in the appendix. Major textual sources include: three provincial public policy reports all of which are authored in the 2000s with the exception of a report on kidneys released in 1985 drawn on for historical comparison; and, three medical guidelines for using living kidney donors from 2000, 2004 and 2006. Annual reports, covering the years 2002-2012, from the provincial organ procurement organization, Trillium Gift of Life Network were also used extensively in the deceased donor analysis. Living donation

textual sources included Anti-Transplant Abuse campaign documents, by which I mean official statements of condemnation by global governance organizations such as the World Health Organization and international-level professional associations such as The Transplantation Society. To understand what happens at transplant centres in Ontario, textual sources included: hospital specific policies, protocols, operating procedures, forms and donor manuals from two adult renal transplant centres (one high and one low volume centre) as well as a living donor ethics guideline from a third high volume centre. To a lesser extent, Canadian Council for Donation and Transplantation (CCDT) annual reports, from 2002-2006, and exemplary media cases were used. Media space is notably shared between the provincial and federal government. As part of the federation of 10 provinces and 3 territories that comprise Canada, Ontario delivers jointly funded healthcare insurance and services. Statistics are drawn primarily from a custom order from Trillium Gift of Life Network's TOTAL database. Interviews with thirty-eight individuals were used to complement textual sources.

The one exception to these sources was the opportunity to act as a participant observer at the Toronto region annual deceased donor kin medal ceremony of spring 2010 hosted by Trillium Gift of Life Network. Families of deceased donors from the previous year were invited to attend and receive a medal on behalf of their loved one as a token of gratitude for their consent to donation. The event was conducted like a collective funeral with speeches, a somber tone of grief mixed with honour and gratefulness. Although this event used to be open to all recipients, this year followed the policy whereby one recipient, this year a singer, spoke and performed for the audience as a representative of all recipients.

In her words and with ample air to sing professionally, she conveyed the life changing significance and heartfelt thankfulness of receiving lungs. A slide show profiled images submitted by participating families of the deceased donors without acknowledging other aspects the audience shared—of the impact of fatal injuries sustained within the same geographic region during the same time period. Each family was invited to the front to receive their medal from the Chief Executive Officer of TGLN followed by a reception.

2.3.1a Interview Process Details

Carleton University Research Ethics Board granted ethical clearance to conduct interviews as part of the research process and no adverse events arose, to my knowledge, as a result. Between June 2010 and April 2011, I alone conducted twenty-nine interviews of thirty-three people with two groups: 12 professionals working in the field (and one former transplant surgeon), 3 other professionals, and 18 people directly touched by transplantation as actual or prospective donors or recipients. The vast majority were individual interviews with the exception of seven 2-person, and one 3-person group interviews. In these cases, the primary interviewee recruited other people, based either on their interest in participating or desire to accompany them (for example, the spouse of a deceased donor recipient). No interviewees received an honorarium for participating. One interview was conducted by video conference (Skype), all others were held in person. Two persons were interviewed twice. Each interview was approximately one and half hour long and was recorded with permission.

The interviews were semi-structured based on an interview guide for which I developed one for professionals and another for people directly affected (provided in

appendix 3). I asked professionals about their role, challenges in achieving goals, current controversies and trends in kidney transplantation. I asked interviewees who were donors or recipients to share their story with me starting with their first involvement in organ transplantation. I then asked questions about relationships, in-hospital experience, long-term health and more specific questions depending on their situation and story.

All direct participants were offered anonymity and are therefore given pseudonyms in the text. Professionals spoke without the condition of anonymity. However, to avoid the distraction of individual identification by readers familiar with members of the relatively small provincial network of specialists, professionals are nonetheless anonymized and numbered by category: “OPO” for organ procurement organization (Trillium Gift of Life Network) staff; “Tx” for Transplant Centre staff, except for staff conducting living donor evaluations, separately categorized as “DT” for Donor Team.

2.3.1b Interviewees Directly Involved in Organ Transplantation

In resuming research on transplantation, I was intent on speaking directly with the people most affected: donors and recipients. I title this category of interviewees as, “directly involved” to encompass the spectrum of participants, including the voices of support people interviewees brought with them to the interview. On four occasions, a spouse or friend attended the interview and were therefore asked for consent and counted as an interviewee.

Trillium Gift of Life Network enabled me to contact this set of interviewees by kindly sending out my call for participants to their Steering Committee for Volunteers (a group of about 12 persons) and their volunteer e-mail distribution-list of approximately

400 e-mail addresses. As a result, almost all participants in this group volunteered for TGLN as organ donation advocates.

The first few interviews were exploratory on my part and I was therefore not particular about what kind of involvement they had in transplantation. Thus, a heart recipient, a second-time liver recipient and a heart-double lung recipient kindly gave me their time in individual interviews. All had, obviously, had deceased donor transplants, and all were involved in promoting organ donation. This group includes the following 18 people, in Table 2, below (those who fit in two categories are categorized only once with a note about the other category in the bracket; support persons are also noted in brackets):

Table 2 *Recipients and Donors Interviewed*

Recipients and donors	Details	
Actual and potential recipients (9 recipients plus 2 support people):	<i>3 Deceased donor kidney recipients:</i>	1 Third-time recipient (also a living donor recipient: her second kidney from her mother failed immediately)
		1 Kidney-pancreas recipient (and his colleague)
		1 Second-time recipient
	1 Second time Potential Kidney Recipient (first deceased donor kidney lasted 13 years, on hemodialysis and the regional wait list at the time of the interview)	
	1 Living Donor kidney recipient (from her sister)	
	<i>4 Deceased donor recipients, other organs:</i>	1 Heart recipient
		1 Third time liver recipient (and his spouse)
		1 Heart and double-lungs Recipient
		1 Double lung recipient
Actual and potential kidney donors (7 people):	<i>3 Living kidney donors:</i>	1 To her brother

	1 To her uncle (adverse outcome, potential lung transplant candidate)
	1 To his brother (7 years later was a dialysis patient, then became a living donor kidney recipient from his female cousin)

1 Potential kidney donor (to her brother)	
1 Non-directed kidney donor	
1 Deceased donor family (parents of a deceased donor child)	

2.3.1c Transplant Centre Staff

I interviewed 11 medical providers from four transplant centres as well as one individual who formally worked as a transplant surgeon. All transplant centres are subunits of larger renal/nephrology programs at major hospitals in Canada's largest cities and medium sized city. Parallel renal units in small cities in Ontario have formal relationships and designated liaison staff with transplant centres in the larger cities. One interview with an assistant at one centre was informal. Two interviewees worked elsewhere in Canada, the remainder worked at one of three transplant centres in Ontario. In the province, based on patient (transplant) volume, the three centres include: two large, urban centres (although donor team interviews cover only one of these centres), and one small centre.

With one exception these individuals can be divided into those caring for patients with ESRD, including dialysis patients, prospective candidates for transplantation and kidney recipients. Although the physicians' patients were not divided by living and deceased donation, when living donation arises, they are on the 'recipient' team and are therefore classified as "RT" for Recipient team members. Three providers were nephrologists whose patients received transplant therapy. They evaluated patients'

eligibility for transplantation and cared for them postoperatively. They were also called upon to care for patients, with whom they usually were not familiar, admitted with postoperative complications as a result of receiving kidney transplant surgery outside Canada. At the time of interview, two were actively engaged in efforts to dissuade potential recipients from transplant tourism. A nurse responsible for pre and postoperative kidney-pancreas transplant patients (all with the primary diagnosis of diabetes) was also interviewed.

The exception was a nurse who worked at a Northern Ontario renal unit whose work, at this small centre, included care for recipients as well as work-ups for potential donors as the liaison to a large transplant centre in Toronto. I count her as a Donor Team interview because of the focus of the interview was on donor evaluation. Another exception was an interviewee who held a senior administrative position at one of the transplant centres (and was involved in the Ontario Renal Network, an agency mandated to prevent and treat renal disease). As her position was in charge of renal patients, she is counted as a member of the RT. ('Donor team' members are, in fact, separated out. By default, all employees are caring for renal patients, therefore are on the 'recipient' side.)

Donor Team members included one nephrologist, two nurses and one social worker. The nephrologist was newly designated to his role as the 'donor advocate'. The nurses dealt exclusively with the donor side of living donation (they would not take calls from potential recipients, for example). The social worker's time was divided between donor team duties (conducting potential donor evaluation interviews) and caring for the larger population of renal patients in the unit. This group is anonymized as a category and

assigned a number, as follows: Renal Transplant Centre, physician or nurse caring for nephrology patients, including renal replacement therapy by transplantation (by default, these workers are on the 'Recipient Team' in cases of living donation) are assigned: Tx1, Tx2; Renal Transplant Centre, Donor Team members are assigned: DT1, DT2, etc.

2.3.1.d Organ Procurement Organization Staff

Given the high number of in-text citations from TGLN, the acronym OPO is used instead to distinguish this group with each individual numbered. A total of seven people are included in this category. Three senior staff and one Organ and Tissue Donor Coordinator employed by Ontario's Organ Procurement Organization, Trillium Gift of Life Network, generously gave me their time for formal interviews. Each interview was approximately one hour and a half. One senior staff member was interviewed twice. Another informal interview was held with a staff member in charge of the Donor Family Program with regards to her postal service work deleting personal information in all correspondence between donor families and recipients. Also included in this group is one former staff member of TGLN's predecessor, the Multi-Organ Replacement Exchange. This group is anonymized as a category and assigned a number, as follows: OPO1, OPO2, etc.

2.3.1.e Related Professionals

Although not quoted, I also interviewed several other professionals with connections to organ transplantation. This included the demographer, David Baxter, and two regional representatives of the Kidney Foundation of Canada. I also had an informal discussion with a key member of the Anti-Transplant Abuse campaign.

2.3.2 *Data Analysis*

The data analysis process integrated all data sources and was iterative. Most importantly, I followed the principles of grounded theory Glaser and Strauss (Glaser & Strauss, 1967). Having spent considerable time on this topic in the past, I was concerned that my previous findings would bias my research process. For this reason, I read theoretical texts throughout the data analysis process and wrote chapter 3, theorizing transplantation, last. My test of the merits of previous theories was whether I could provide a more fulsome account of current findings using other theories or not. This may not have been a perfect process but the discovery of similar findings confirmed and advanced my thinking. The theories that stayed were those that aided in the analysis.

A more pragmatic account of data analysis is this: The first ten interviews were listened to, clipped and coded using *Stories Matter* software developed by oral historians at Concordia University. Once all interviews were completed, they were selectively transcribed. As a result, I continually returned to either a clip or section of a transcript. Next, all data sources were examined together: texts, statistics and interview clips or transcripts and sorted into two categories: deceased donation and living donation.

The analytical technique was to identify and continually refine themes through repeated readings. Here I followed Monica J. Casper and Lisa Jean Moores' (2009) idea of seeing as central to knowledge production and biopolitics in their book *Missing Bodies: The Politics of Visibility*. They seek to draw, "...our attention and analytic gaze to the often-marginalized bodies, individuals, and groups that erase their voices and bodies..." (Casper & Moore, 2009: 15). The pair convert their objective to see bodies into a methodology they

call an *ocular ethic*, which is a “new legacy of looking: one that refuses to assign political value to some bodies at the expense of others, one that treats ‘human subjects’ in the fullness of their lived, embodied experiences” (Casper & Moore, 2009: 14).

2.3.3 Ethics

As noted above, the interview process conducted for this project was approved by the Carleton University Research Ethics Board. Separate consent forms were used for professionals and people directly involved as potential or actual donors, deceased donor kin, recipients and companions brought along to the interview. Professionals were asked to reveal public information and were therefore not granted condition of anonymity. Anonymizing this set of interviewees was my decision made during the writing process. This was done to minimize the potential distraction of identifying specific individuals by readers familiar with the small OPO and nephrology community in Ontario. By comparison, people directly involved were granted anonymity, informed of their right to not reply to any questions asked and withdraw from the interview at any point. Disclosure included acknowledging that the potentially sensitive nature of asking them to share and asking questions about their kidney transplantation story carried a risk of harm. Methods for dealing with harm should it arise were identified. No adverse events were reported.

2.3.4 Limitations

The limitation of a geographically fixed approach is its specificity. It will speak most immediately to how organ exchange occurs in countries with highly developed medical

systems, access to health care and drugs, and regulatory control that accept brain and heart death. This excludes, for example, the perspective of organ sellers and the more common global context of mixed public/private and private health care industry.

When looked at along the deceased donation and living donation divide, it is important to note a caveat: the data I draw on my analysis of living donation in chapter 8 are limited. While there is sufficient evidence to demonstrate my argument, my findings should be read with caution. To gain insight into kidney exchange experiences by those most affected, the study includes eight interviews with people directly involved with living kidney donation as actual or potential, donors or recipients (and one who was both a live donor and later a live donor recipient). To learn about medical intermediaries, I conducted eight interviews with donor team health professionals at three transplant centres in Ontario. Both sets of interviewees, direct participants and intermediaries are notably limited.

Another note of caution is to recognize that the tone and possibly the purpose of the public policy reports used in the study may change over time. For example, there is a definitive shift evident in the CCDT annual reports from a comparatively plain report to highly stylized report the following year. Less information is provided when the goal of the report is promotional rather than public accountability.

2.4 Conclusion

This chapter has reviewed critical social science literature on organ exchange for transplantation following four streams that emerged in relation to the altruism versus markets framework established by Richard Titmuss' analysis of the organization of blood

systems in 1970. I categorized these streams as; (a) altruism corrupted by the organ shortage; (b) capitalism versus altruism; (c) beyond the binary; and (d) the organizational gift. I identified compelling arguments throughout and gaps in the literature situating this study with the ‘beyond the binary’ scholarship. The theoretical tools were then presented followed by the methodology and data used in the study. Using the foundations established in this chapter, next I offer a theoretical account of how transplantation works in chapter 3 and a concrete picture of Ontario’s donors, recipients and intermediaries in chapter 4.

Chapter 3 Theorizing Kidney Exchange

Given my problematic that how kidneys are acquired does not appear to be subject to the kinds of scrutiny and evidence-based debate that are reasonably warranted, the first task is to establish a comprehensive understanding of how kidneys become available and are exchanged from dying and living persons. In this chapter, I put forward my argument that kidney exchange in Ontario is complex with respect to donors because of the tension that is created between the demand for kidneys and the constraints on its supply: kidneys must be relinquished without causing harm. When we turn to examining simplifications, controversies and caveats in deceased donation (in chapters 5 and 6), and the negotiations over living donor protection (in chapters 7 and 8), it is alienability (that is, the legitimacy of organ removal, as explained below) that causes trouble more than the gift – market debate. For this reason, the general account of both sources of kidneys (from the living and dying) that follows allows me to make distinctions regarding altruism and alienability that are important to later chapters. I also show the kind of complexity that I argue attention is deflected away from.

Few scholars have offered an account of how organ exchange works. In addition to Philippe Steiner, Kieran Healy and Graciela Nowenstein (reviewed in the previous chapter), it is Lawrence Cohen's (2005) book chapter, "Operability, Bioavailability, and Exception," regarding India (drawn on in the next chapter) that inspire my own account. The approach taken here is 'beyond the binary' of the altruism-market framework. It draws from the theoretical tools identified in the previous chapter regarding commodification and knowledge as directional.

The process of objectification at the heart of transplantation entails three parts: 1) morbidity and mortality patterns influencing the size of potential donor pools among the living and dying; 2)

the creation of rules of altruism and alienability that enable yet limit the dimensions and characteristics of the pool; and 3) these rules inform means of converting potential donors into actual donors, including an orientation towards those in need of organs which I call recipient-centrism. Altogether, I see this process of generating a supply of organs as complex: the size of the potential donor pool is a fundamental variable unamenable to social intervention; the rules aim to contain the threat that kidneys will be valued ahead of persons; and multi-directional dependencies – recipients on donors' willingness to consent, and donors on intermediaries' ability to ascertain with certainty that kidney removal will not cause harm.

The two variables I ascertain as most determinative of kidney exchange in Ontario are altruism and alienability. This shifts the dominant frame of reference from gifts versus markets to bring alienability into view. I understand altruism as the exchange of a kidney for psychological benefit, and alienability as the legitimacy of removing one or both kidneys on the grounds that this organ is not too precious or vital to the life of the donor. Alienability hinges on the psychological and physiological attachment of the owner. It also rests on donor eligibility criteria set by medical intermediaries who weigh the impact of removal on the donor as well as the quality (thus value) of the kidney to the recipient. Although all three aspects of alienability are necessary in deceased donation, the legitimacy of organ removal rests most on the act of marking the end of personhood through death declaration.

In my account there are five necessary and enabling dimensions to acquiring organs. The first two reflect the embeddedness of transplantation in any given society: the choice of investment; and medical authority and jurisdiction over certain bodies. Third is therapeutic demand and success. The latter two focus on organ supply by addressing the process of objectification for kidneys. I analyze this process as involving two interrelated steps identified above: 1) the

identification of a pool of potential donors (sources of organs); 2) followed by the conversion of potentials to actuals. Both proceed based on rules which are jurisdiction and system specific. It is the story of how the rules – of altruism and alienability – came into being that I follow. Here, what makes organ removal legitimate is the boundary-work of limit-setting reflected in the rules that include and exclude persons from the pool of potential donors and establish legal requirements and medical guidelines to convert them into actual donors. To deepen the analysis in this chapter and foreground distinctions that arise in subsequent chapters, my account takes another step by differentiating the rules into two categories: ‘rigid’ rules are considered social and are established in law; ‘pliable’ rules, are considered scientific and fall under the domain of medicine.

At the nexus of the donor complexity I describe is a tension between donors, intermediaries and recipients which I argue is revealed in the rules contained in *Gift Acts*. While I contend that tension exists in all governing rules, here I show only how this occurs in the legislation that enables and constrains kidney exchanges for transplantation in Ontario and similar jurisdictions. (Chapter 7 shows how this is revealed in ‘pliable’ rules of medical guidelines). Herein are clauses of donor (and intermediary and recipient) protection that convey the perception, with which I concur, that transplantation creates an inherent threat of valuing organs ahead of the persons within whom they originate. While alienability sets some kidneys free, the rules of altruism are intended to contain the threat of its value; but both are necessary for transplantation to proceed. More specifically, while altruism comes to be viewed narrowly as a prohibition against kidneys for cash, I argue that all four rules of altruism (consent, terms of exchange, privacy and death declaration) and two of alienation (death diagnosis and living donor beneficence over non-maleficence) are formative, act as donor protective constraint on efforts to increase organ volume, and represent political sites.

The argument follows the chronology of major historical events and their implications on the field, interrupting this flow to make the more distilled argument. This high-level overview of deceased and living donation fundamentals is followed by a brief section distinguishing Ontario's system of altruism from other possibilities. This foregrounds the analysis presented in chapter 7 which continues the thread started here by showing how contemporary actors campaign for nation-based transplantation systems in every jurisdiction modelled along these lines. Where this chapter stops is prior to examining the explicit pursuit of organs and approval of exchanges addressed for deceased donation in chapters 5 and 6, and, for living donation, in chapters 7 and 8.

3.1 Acquiring Organs

My reading of the history and contemporary practice of transplantation identifies five key developments, listed in Table 3, that are necessary and enabling while revealing the complexity of transplantation. Each one is a source of ongoing pursuit.

Table 3

Necessary and Enabling Developments for Transplantation

1.	Investment
2.	Medical authority and jurisdiction
3.	Demand and Success
4.	Pools of potential donors and access to them
5.	Techniques to convert potential donors to actual donors

As the first three developments are aspects of complexity related to but not specific to donors, I review them quickly and more superficially than they deserve. Future research is warranted to take up and expand on these matters. The first development, then, is investment by private and public sources to fund the development of surgical techniques and immunosuppressant pharmacology, and at minimum institute an enabling legislative framework for organ removal.

Deceased donation also requires ventilator machines and the establishment of work systems as well as co-ordination to at minimum link two different hospital units. These factors are expanded in Ontario, between 2000 and 2014, and involve the following investors: leading pharmaceutical multinational corporations such as Novartis, Roche, Astellas (who provide immunosuppression drugs and sponsor transplant research, journals and events); the federal government through the Canadian Council on Donation and Transplantation, 2003-2007, and Canadian Blood Services, 2006 to present; and the provincial government through the Organ Procurement Organization, Trillium Gift of Life Network, 2002 to present (with a preceding organization, Organ Donation Ontario and before that Multiple Organ Retrieval and Exchange). An analysis of Ontario *Gift Acts* follows. This is the primary legislation that enables and constrains transplantation.

Second, medical authority and jurisdiction over potential donors is central to transplantation. Potential living donors and deceased donor kin must trust in medical knowledge that organ removal will not inflict harm. And overseeing death must be the accepted role of physicians, not priests. As Timmermans (2002) identifies, transplant authorities are also enabled by the ability to remove organs from potential deceased donors that come under the authority of coroners for crime investigations. By extension, the longstanding norm of medical autonomy enables medical teams at transplant centres to have the final say on living donor eligibility. When controversies arise between practitioners, it is medical science that is claimed to be the arbitrator. This insulates any therapeutic modality from claims that decisions are social rather than scientific.

The third development identifies demand and success as necessary and intertwined. Success thanks to the development of cyclosporine in 1982 led to increased coverage of transplantation by private and public insurers, the opening of new transplant centres, and an ongoing stream of research expanding the range of diseases treatable by transplantation (as well as the number of

body parts that can be transplanted) and improving its success.¹¹ This is one way more patients become eligible for transplantation. In transplant literature, this is referred to as the paradox of success: that positive treatment outcomes contribute to a desire to treat more patients using the same therapeutic modality. What holds back the expansion of transplantation is dependence upon a steady supply of organs. A side-effect is that more transplant centres led to competition for patients and for organs (TTS, 1985).

As identified in the subsequent section on kidney disease, sources of demand are nevertheless multiple, emerging also from epidemiological trends as well as an ageing society. When I asked my interviewees about the demand for kidneys, one answer was, “we didn’t bother to test for chronic kidney disease for people over 70 in the past” (DT3), another was, “patients are surviving other diseases and those treatments take a hit on the kidney” (DT4). And, in chapter 6 another possible contributor to demand is identified suggesting that by wait-listing patients when supply is high, transplantation is supply not demand-driven. The other key developments are about the existence of potential donors and having the authority and jurisdiction to access these pools of people for organs.

The demand for organs exceeded supply by the early 1990s leading some observers in the United States to declare, in 1991, the situation known as an “organ shortage crisis” (Renée C. Fox & Judith P Swazey, 1992). Since this time, the problem of shortage has driven the search for organs. And, as we see in chapter 5, by 1999 in Canada and 2000 in Ontario, the supply shortage defines the standard approach to transplantation which is organized around the promotion of organ

¹¹ Note that national regulators approved cyclosporine for use at different times. It was first approved in the United States in 1983.

donation. The variables identified here recognize, however, that while the shortage emerges from the genuine need of End-Stage Renal Failure patients for treatment, it is also the product of demographic shift, the social construction of wait-listing practices and a constellation of investors, public and private, whose interests are tied to the expansion of this therapeutic modality.

3.1.1 Pools and Rules

What I see as the fourth and fifth developments necessary and enabling for transplantation is the creation of pools of potential donors and gaining access to them; and, techniques of converting potential donors into actual donors. This is done, in my analysis, through the creation of limit-setting rules that enable by setting boundaries and codes of procedure that manage the inherent threat that organs acquire value ahead of persons. My emphasis in analyzing the history of transplantation is to focus therefore on the rule-making that follows three key moments. In doing so, I categorize the type of rules made, as ‘pliable,’ to refer to medical practice, broadly construed, which is standardized and made authoritative through the release of practice guidelines, or ‘rigid,’ as encoded in law.¹² I made this distinction in the types of rules in order to show how some rules but not others are pushed by the recipient-centric effort to increase the volume of kidneys available for transplantation. In this chapter I only go as far as identifying the rules, showing how they evolved, historically, and distinguishing how these rules shape permissible pools of donors in Ontario distinction from other regimes in China and Iran as well as illegal commercial markets. What follows then is, first, a review of the history of transplantation, followed by summarizing the

¹² Note that I use medical guidelines to refer to consensus statements, protocols and similar documents which serve as to legitimize some practices and sometimes delegitimize others.

rules (Table 4), and summarizing the global pools of potential donors (Table 5). Subsequent chapters examine how organ donor systems work within and push the rules.

The standard history of transplantation is marked by a list of medical breakthroughs. The three key turning points important for kidneys are: 1954, the first successful living donor kidney transplant from identical twins; 1967, the first successful deceased donor transplant, of a heart; and, the advent of cyclosporine, around 1982, the first drug to suppress immunological rejection enough to extend graft survival and recipient lifespan sufficiently to shift transplantation from an experimental treatment to an accepted, therapeutic treatment.

3.1.1a After 1954: Living Donors and the Rigid Rules Encoded in 'Gift Acts'

In the early 1960s, legislators passed “Gift Acts” enabling organ transplantation by enshrining rules aimed to protect the three parties involved: donors, most importantly, but also physicians as the intermediary and recipients. Such laws began in Ontario with *The Human Tissue Act*, 1962-63, followed by *The Human Tissue Amendment Act* 1967 and *Human Tissue Gift Act*, 1971. Four key provisions include: 1) establishing permission and limitations on who can give consent; 2) requiring two physicians without any association with the proposed recipient establish, “the fact of death...in accordance with accepted medical practice;” 3) a provision for privacy (individual-level non-disclosure in deceased donation) (“The Human Tissues Gift Act,” 1971); and, 4) a prohibition on sales clause is part of the 1971 Act and has remained unaltered since then:

No person shall buy, sell or otherwise deal in, directly or indirectly, for a valuable consideration, any tissue for a transplant, or any body or part or parts thereof other than blood or a blood constituent, for therapeutic purposes, medical education or scientific research, and any such dealing is invalid as being contrary to public policy. (“Ontario, TGLN Act, c. 39, s. 7, 10,” 2000)

While it is the prohibition of sales (“valuable consideration”) that has become contested, I argue that all four clauses of consent, death declaration, privacy and sales set the foundations of altruistic kidney exchange.

First, in the case of consent, in chapter 8 we see that ensuring consent is genuine is not always straightforward for nephrologists who act as living donor advocates. Second, with respect to death declaration, in my analysis, this ‘rigid’ rule that two separate physicians must declare death is revealing. It acknowledges the perception that organ transplantation carries an inherent threat: given their value to others, organs may hold greater value than some persons. The threat is implied to be held by physicians caring for potential recipients, who now have a vested interest in dying patients as a pool of potential donors and thus a source of organs. But rather than prohibit transplantation altogether, as Japan did for deceased donation for thirty years (see footnote 3), the rule manages the threat to allow use of this source. Notably, the makers of these ‘rigid’ rules allow the alienability of organs to be determined by ‘pliable’ rules. In case knowing what constitutes death changes, which it does, the present or absence of death will be declared “in accordance with accepted medical practice.”

3.1.2a After 1967: The ‘Pliable’ Rules of Medicine

Following the 1967 first deceased donation, medical experts released sequential diagnoses for brain death (changed in 2006 to NDD for Neurological Determination of Death) starting in 1968 (refined and released for Canada in 1967, 1974, 1987 and 1999).¹³ In my previous work

¹³ For details see McKay, 2001, pages 76-80. The first heart transplant in 1967 captivated world attention. Margaret Lock (1989, 1995a, 1995c, 1996a, 1996c, 2002) has extensively analyzed the initial rejection (including criminal charges laid against the physician) and public debate spurred by the removal of a heart for transplantation in Japan compared to what she called “the ease” with which deceased donor organ removal for transplantation was accepted in Western countries.

(McKay, 2001), I argued that the goal of this process was to legitimize organ removal by marking a point in time after which personhood is absent which ensures that organ removal cannot be perceived as causing death. Known as the “dead donor rule,” this code of practice establishes the alienability of deceased donor organs: body parts are no longer needed by the dying person once diagnosed and declared officially dead.

I interpret diagnoses, along with similar texts, such as protocols, as forms of medical practice guidelines that seek to standardize practice and therefore constitute a set of ‘pliable’ rules. These rules are formed through medical means of establishing legitimacy. The process is characteristically a conference of experts who produce a consensus statement based on a review of relevant scholarship. Subsequent research studies further substantiate or challenge aspects of a statement until a new iteration is released. Such rules carry no means of enforcement other than to influence the regulation of the practice of medicine by professional self-regulatory bodies such as The College of Physicians and Surgeons of Ontario. Practice guidelines must gain acceptance within the medical community and by patients who will be subjected to them, but they do not require public consent in the same way as the development of law through the legislative process in a democracy.

3.1.3b After 1982: Cyclosporine

Lawrence Cohen (2005) correctly identifies the development of cyclosporine a decade later as a watershed; successful suppression of the immune system reduced the need for ideal matching. It was on account of cyclosporin (approved in the United States in 1982) that the door to who could provide a kidney – living or dead – flew wide open. Improved results using deceased donors reduced the justification of using living donors (the balance of beneficence and non-maleficence

to living donors was heavily debated at the time) (Starzl, 1985). Further, as is Cohen's emphasis, success made transplantation mobile.

In the experimental era of transplantation, from 1950 to 1982, there were reported instances of familial and prisoner coercion, and commerce in the acquisition of kidneys from live donors (Starzl, 1992). It was in the mid-1980s that kidneys became commodities through purchases and sales within national and international markets. Between 1984 and 1988, 130 patients from the United Arab Emirates and Oman traveled to Mumbai to buy kidneys from living unrelated donors, each of whom received US\$2,600 to \$3,300 (Salahudeen et al., 1990; Scheper-Hughes, 1992). In the United States, private, for-profit transplant centres acquired voluntarily donated deceased donor kidneys and advertised to bring patients from other countries to the United States for surgery. Some of the kidneys were also exported to similar transplant centres in Europe (TTS, 1985). In Kopytoff's (1986) terms, successful immunosuppression reduced the singularity of kidneys as objects of value and kidneys acquired greater generic-ness as long as the limits of blood-type compatibility and donor-specific antibodies were respected.

The emergence of full-scale markets in kidneys caused a reaction by parties whose stakes were high and for whom sales were considered "unethical" and therefore threatening to the legitimacy of transplantation. This response led to new limit-setting rules by professional bodies and national legislatures. In the first public position statement of a transplant organization, the preeminent international transplant organization, The Transplantation Society (1985) (TTS), condemned the development of a "climate of commercialization." And, further condemned providing access to organs based on the ability to pay and for betraying the expectations of donor families and wait-listed American transplant candidates.

Bolstering the defining of altruism in Gift Acts, The Transplantation Society declared, “that the donation of an organ is a gift of extraordinary magnitude and that transplant surgeons hold a donated organ in trust for society” (TTS, 1985). The organization was concerned about the, “ramifications for transplantation as a whole” (TTS, 1985). Betrayal of consent is also key: people give consent based on an understanding of where and to whom their donation will go. In chapter 7 I show how this statement becomes the first of a series spanning two decades that evolves in the 2000s into an anti-transplant abuse campaign.

It is the actions of Dr. H. Barry Jacobs, however, that is considered to have provoked congressional hearings and legislation in the United States. In 1983, Jacobs established a private enterprise, International Kidney Exchange, Ltd., and advertised his offer to broker for-profit kidney contracts to 7,500 hospitals (Joralemon, 2001; Waldby & Mitchell, 2006). The legislative process led to the United States’ Public Law 98-507, *The National Organ Transplantation Act*, which made the acquisition or exchange of human organs for valuable consideration a federal crime. The key term of prohibition was the same as in the 1962-63 Ontario *Gift Act*, that organs could not be exchanged “for valuable consideration.” The clause “buy, sell or otherwise deal in, directly or indirectly,” also, notably, applied the law broadly to donors, recipients and intermediaries. In his research, anthropologist Donald Joralemon (2001: 30) found the 1984 hearings and legislation were characterized by “a remarkable ethical consensus around the world that one should not buy or sell human organs.” Below I summarize and further analyze the rigid and pliable rules and locate how these rules shape the pools of potential donors in Ontario compared to the other organ exchange regimes.

3.1.2 The Rules of Altruism and Alienability as Rigid and Pliable

The rules made after establishing living and deceased people as pools of potential donors and cyclosporine making transplantation mobile are summarized in Table 4. These are the parameters that have defined transplantation in Ontario and similar jurisdictions as altruistic organ exchange regimes.

Table 4 *Legitimization: Limit-Setting Rules in Ontario*

	Category	Purpose	Rule	Source of Legitimacy	
				Live Donation	Deceased Donation
1	Rigid	Authority based on Ownership	Consent	Legislation	Legislation
2	Rigid	Terms of Exchange	Prohibition against sales	Legislation	Legislation
3	Rigid	Privacy	Non-disclosure of consent/refusal and donor-recipient identities	-	Legislation
4	Rigid	Alienable	Determination of death	-	Legislation (two physicians separate from transplant team)
5	Pliable	Alienable	Death diagnosis (brain, heart)	-	Medical Guidelines
6	Pliable	Alienable	Balancing beneficence and non-maleficence	Medical Guidelines (two separate teams)	-

Looking at the six rules as a whole, what is notable is that advocates for increasing organ volume come to criticize the terms of exchange as too restrictive and this sole rule comes in many ways to define altruism. As a consequence, attention is deflected from the rules that establish alienability. Herein, the point of differentiating two types comes to the fore: What makes a kidney available for removal then, potential donor eligibility criteria, as documented in medical guidelines, is separate from consent, privacy or the terms of exchange. This means that pliable rules can change without disrupting rigid rules.

With respect to the differences illustrated in Table 4 between the rules governing deceased and living donation, we see that in deceased donation, alienability of the kidney is established through both rigid and pliable rules. As analyzed above, the legitimacy of diagnosing death is

conducted according to medical guidelines, even though its declaration must legally be performed by two physicians who are not part of the care of the potential recipient.¹⁴ The alienability of a kidney from a living donor is similarly determined based on medical guidelines. In this case, it is not death that makes kidney removal acceptable but that more good than harm will come from the exchange for all parties, especially the donor. This is described as follows by The Multi Organ Transplant Program at the Toronto General Hospital:

In transplantation, the benefit to the recipient is greater than the benefit to the living donor. It is acknowledged that the benefit to the donor is primarily psychological, i.e. increased self-esteem and sense of well-being resulting from helping another individual. In balancing beneficence and non-maleficence, the program strives to minimize risks, maximize benefits, and facilitate autonomous decision-making by maintaining a high standard in the process of obtaining informed consent (University Health Network, 2008).

As I show in chapter 7 and 8, the exchange system we call altruism, which relies also on alienability, is constituted for living donation through the creation of medical guidelines and their implementation (or not) at transplant centres. The processes of creating such documents and the centres are sites of negotiation and contestation where, in Ontario, mostly pliable rules apply.

In chapter 8 we also see that transplant center mediators of live donor kidney exchanges desire this separation to minimize the challenges that arise from the relationality between the potential donor and potential recipient. I agree with Nancy Scheper-Hughes (see chapter 2) that while the aim of privacy is to protect parties from the harm that could arise from the kidney exchange, this rule may indeed contribute to an unintended consequence of attention deflected

¹⁴ What makes organ removal from the dying feasible is the work task called “donor maintenance” which keeps the organs alive in the dead person prior to removal. As we see in chapter 6, the protocols guiding organ removal from the living are also based on the ‘pliable’ rules established in medical guidelines.

from the relationality of donors to recipients. Privacy inhibits learning about deceased donor stories which at a societal level means the dependence for organs upon the antecedent events (often violent) that lead to catastrophic neurological or cardiac conditions.

3.1.2a Rules Create Pools

A few points are important to viewing rules as techniques of creating pools of potential donors and converting potentials into actual donors. What Table 4 illustrates (along with Table 5 below) is that while creating the pool of potential donors hinges on societal and biological criteria, it is a social construction. Seeing and classifying people as ‘potentials’ is narrow or broad in scope and targeted towards some and not others based on societal characteristics (how and where people die, and/or need money) through the filter of rules. And, the process of converting potentials into actuals is similarly constructed through rules.

In my view, taken as a whole, the rules reveal a tension between the interests of donors, intermediaries and recipients that exists regardless of the mode of exchange. Donors and recipients stand to benefit from the renal capacity of the kidney; the intermediary mediates the interests of these two parties while possessing its own objectives. Transplant centres (supported by the range of investors identified earlier) seek to facilitate as many transplants as possible as long as these exchanges do not compromise legitimacy. Physicians and centres want to be protected from lawsuits accusing them of murder or malpractice as well as bad publicity from poor outcomes.

What is also notable and touched upon earlier is that, with the exception of legislation requiring that two independent physicians declare death, rules established by legislation are classified as social and fall into the public domain. By contrast, rules established by medical guidelines are classified as scientific and fall into the internal domain of transplant experts. This reflects what Bruno Latour (1993) called ‘the great divide’ in western society between the social

and scientific. Further, where guidelines and thus medical science is the authority, there is more room to maneuver. As Table 4 shows, the rules around alienability are eligibility criteria that are set not through public process but through following the codes of medical knowledge-making.

3.1.3 *The Fundamentals of Kidney Exchange Compared*

As a brief aside, to put Ontario in context, Table 5 lists all possible categories of potential kidney donors identified internationally and over time, including into the future.

Table 5 *Pools of Potential Kidney Donors: All Possible Sources, 1954 to 2014*

Live	Deceased	Future
Family (Biologically related and unrelated members, e.g. spouses) Friends Acquaintances Strangers Employees Prisoners Minors Religious adherents Medically complex donors (with, for example, well-controlled hypertension, mild obesity, stable psychiatric disorders)	*Ventilated patients with a catastrophic neurological condition Prisoners condemned to death Infants (anencephalic newborns) Elderly Expanded criteria donors (with medically compromised organs)	Xenotransplantation combining human cells grown in pigs or primates Artificial organs made from human cells

Notes: *These patients are in hospital (or, in some places, ambulances) and their condition is a result of illness or injury isolated to the brain or heart, such as head trauma or heart attack. They must meet criteria for either Brain death (also known as NDD for Neurological Determination of Death) or heart death (also known as DCD for Death by Cardiocirculatory Determination) which is further sub-divided into controlled or uncontrolled. Only controlled DCD is practiced in Ontario during the period under study.

What this table identifies is the wide range of possibilities and, therefore, the importance of rules in shaping whom, among these categories of people, becomes a kidney donor. We see in the next chapter a profile of Ontario's kidney providers. As a population, Ontario's donors are almost entirely altruistic but a small number come from other jurisdictions as a result of Ontarians travelling outside the country to purchase kidneys in China and in illegal markets.

Thinking about commercial providers in other countries who provided a kidney to an Ontarian is a concrete way to contrast the 'pools and rules' of non-altruistic regimes to the 'pools

and rules' here. Prasad and colleagues (G.V. Ramesh Prasad, Shukla, Huang, Honey, & Zaltzman, 2006) studied 28 recipients who bought kidneys outside Canada through a commercial exchange between 1998 and 2005. From this study, five people were found to have provided kidneys to Ontarians in East Asia. They were likely to be Chinese prisoners who became deceased donors. In China, a state-capitalist/authoritarian model may be the best way to describe the use of death row prisoners as the primary pool of deceased donors whose kidneys are sold on an international market. The Bellagio Task Force Report on Transplantation, Bodily Integrity, and the International Traffic in Organs (Rothman et al., 1997) documents how using prisoners was enabled. According to this source, a rule was implemented in China in 1984 after the introduction of cyclosporine titled, "Rules concerning the Utilization of Corpses or Organs for the Corpses of Executed Prisoners." The rule stated that, "corpses or organs of executed prisoners could be harvested if no one claimed the body, if the executed prisoner volunteered to have his corpse so used, or if the family consented" (Rothman et al., 1997).¹⁵

Another seventeen individuals in South Asia, Southeast Asia and the Middle East relinquished their kidneys to Ontarians. In these locations, and in other parts of the world, there are national, international and transnational illegal markets in kidneys sometimes involving trafficking of persons (addressed in chapter 7). In general, strangers exchange money for a kidney with profit made in-between. A third contrasting model exists in Iran. Here there is a state-supported regulated monetary living donation model. It relies on strangers as the pool of potential

¹⁵ Original source cited in the Bellagio Task Force Report is Human Rights Watch/Asia report, Robin Munro chief author.

donors and monetary terms of exchange within a nationalist kidneys-for-cash market (Bagheri & Delmonico, 2013; Ghods, 2008; Tober, 2007; J Zargooshi, 2001).

With respect to proposals for a regulated, monetary market for living donation in Canada or the United States, the pool of potential donors shifts from concentric circles connected to a specific transplant candidate to persons who needs money. Techniques of conversion rest, similarly on psychological benefit versus the need for cash. Notwithstanding the debate over which model expands the pool, conversion also rests on the pliable rules: potential living donors must meet donor eligibility criteria based on medical guidelines regardless of the terms of exchange.

In Ontario, to adhere to the rules of altruism and alienability, the pools of living persons drawn on are overwhelmingly family but are diversifying. As we see in the next chapter, statistics collected on living donors show a rise in the “unrelated” category, which includes family members such as spouses and in-laws.¹⁶ It also includes friends and acquaintances donating as “emotionally (un)related” donors. Usually strangers donate to a specific potential recipient anonymously, there is one case of public solicitation and one case of a religious adherent, a Buddhist monk, brought to Canada from Burma to donate to an Ontarian (and, we see in chapter 8 another case of a religious adherent, this time from Australia, who was denied) (DT5). Minors and prisoners do not meet consent criteria in Ontario. Whether the other categories of donors – employees or medically complex donors – qualify to donate is unknown.

Ontario’s pool of potential deceased donors comes from the population of persons on ventilators, in hospital diagnosed with a catastrophic neurological condition. In my previous

¹⁶ Given that the classification scheme is designed to monitor recipient outcomes, biological criteria shapes categories ahead of social criteria.

research I documented and analyzed the ‘pliable’ rules of medical guidelines that established brain death as death specifically for Canada (McKay, 2001). Medical anthropologist Margaret Lock (2002) provides a more general account for Canada and the United States juxtaposed with Japan where brain death was not accepted until 1999. We see in the next chapter the diagnoses that fall under the larger category of catastrophic neurological conditions, from 1966 to 2010, of sudden illness such as strokes or injuries causing head trauma from vehicle crashes. The rule that applies to this pool of potential donors is that they meet criteria for brain death. Controversial donors within this pool include elderly donors, expanded criteria donors and anencephalic newborn infants for whom application of the brain death diagnosis was a topic of debate in the early 1990s.¹⁷

As noted in the introduction, the major change in Ontario (and Canada) during the period of 2000-2014 is the expansion of donor eligibility criteria. For deceased donors, the pool of potential donors increased following the release, in 2006, of medical guidelines titled, “National recommendations for donation after cardiocirculatory death in Canada” (Shemie et al., 2006). This legitimized using heart-based criteria for diagnosing death instead of brain-based criteria. And, the first DCD case the same year was publicized and experienced by the donor family as a positive development.

3.2 Techniques of Conversion

The third part of objectification is converting potential donors into actual donors. Although intermediaries can do nothing to influence the size of the deceased donor pool, other than alter its

¹⁷ In 1992 a Law Reform Commission of Canada report addresses the controversies regarding diagnosing anencephalic infants as brain dead (Law Reform Commission of Canada, 1992).

boundaries, it is up to them to do the work of conversion. We see in chapter 6 that, following other OPOs, TGLN embraces this understanding of the scope of their work by developing a conversion metric to monitor organizational performance.

If we look back at Table 4 as our guide, we can see that whatever the rules are, conversion is about implementing these rules. In Ontario, TGLN and transplant centres must follow the ‘rigid’ rules of altruism to 1) secure consent; 2) ensure donors and recipients are not exchanging money; 3) ensure privacy is maintained; and 4) ensure that death is determination by two physicians separate from the transplant team. With respect to the ‘pliable’ rules of medical guidelines, conversion requires that potential donors meet donor eligibility criteria. Tests must affirm that the kidney is immunologically compatible and of sufficient quality to be of benefit to the recipient.

Medical guidelines for converting deceased donors require the development and implementation of a series of hospital-level protocols and procedures. In addition to a number of logistical details, protocols ensuring donor eligibility include key steps such as diagnosing death (by either NDD or DCD criteria), declaring death (by two independent physicians) approaching the family for consent, biomedical testing and for ICU/CCU staff to perform “donor maintenance” which ensures the organs remain alive. Even with healthy organs, if the dying patient fails to meet death criteria while their organs remain vital they fail to meet deceased donor eligibility criteria. It is timing that is central in this instance to the process of demarcation that establishes alienability of kidneys based on death. In living donation, potential donors are converted into actual donors by meeting living donor eligibility criteria; intermediaries must ascertain with certainty that kidney removal will not cause harm.

Following Hoeyer (2013) I interpret the work of conversion by a range of actors (including donors, recipients, advocates and especially intermediaries) as co-constituted by ideas and the

material. Above we can see already how concrete practices enable and are necessary to kidney donation. Below I present my concept of recipient-centrism which draws on theories of knowledge as directional identified in the previous chapter. The ensuing and last section briefly demonstrates how the ideational, specifically recipient-centrism, is structurally embedded this time by pointing to the mandate of intermediaries. First I describe how I arrived at the concept of recipient-centrism and explain why I consider it useful.

3.2.1 Ideational: The Concept of Recipient-Centrism

Necessary for conversion is an awareness that one possesses something of value to someone else, and then consenting to donate it, if it is available. In Ontario, the ‘rigid’ rule regarding consent is a legal requirement of explicit consent which creates a need to persuade donors (unlike presumed consent). In the previous chapter I identified the theoretical sources of sociological approaches that consider knowledge as directional. Here I show how these theories led me to develop the concept of recipient-centrism as an orientation in thinking that inserts the ‘other’ in the life of or treatment of the potential donor. It interpolates owners to become organ donors and justifies intermediaries removing kidneys for transplantation.

In my previous study on brain death for transplantation, I argued that “transplantation re-orientes the medical gaze from a singular to a ‘double gaze’ by positioning patients as subjects and objects of medical intervention; seeking treatment as well as providing the material needed to treat others.” (McKay, 2001: 13). Exclusively addressing how deceased donors are constituted, the concept of a *double gaze* was my own creation, used to describe the situation of physicians looking at certain dying patients—those classified as potential donors—in this light: as not only subjects to be saved through the application of medical techniques but also as repositories of valuable

organs needed to treat other dying patients. Through transplantation, the job of physician (and, by extension, of hospitals) is no longer only to treat the ill but to generate the “medicine” of organs to heal other patients. In 2014 this rings even more true as annual audits are released measuring the organ output of individual hospitals (see, for example, donor counts and conversion rates by hospital and region, TGLN, 2012).

To illustrate the concept of a *double gaze* two instances from my previous study are briefly conveyed, one from 1969/1972 and the other from 1999 (for the full analysis see chapters 2 and 5, McKay, 2001). In 1969, Dr. Christian Barnard hosted a symposium of transplant surgeons. The event closed with a second mention of the problem of donors. Two solutions were made: forming linkages to emergency wards *to constantly remind physicians of the needs of other patients* and securing legal consent in life for automatic retrieval of organs (Shapiro, 1969). At a similar conference three years later it was remarked that,

Doctors responsible for the care of the fatally injured have *a secondary responsibility to the community* to assist the transplantation programme by selecting and caring for potential organ donors. If they decline this responsibility, they *deprive potential recipients* of any chance of further useful life by making standard methods of organ transplantation logistically impossible (G.C. Oosthuizen, 1972: 55, emphasis added).

Precisely the same kind of seeing ‘double,’ – thinking of two patients, no longer just one – was articulated, in Canada, in 1999. During an exchange between three dissenting witnesses who argued that brain death is not death and Members of Parliament, one member, the Honourable Mr. Keith Martin (a Reform Party Member of Parliament, physician and public advocate of organ donation), directed this question of clarification to medical experts called upon to testify based on their greater knowledge of the subject matter:

[Please explain to the committee]...whether in transplant surgery you would have a much greater chance of having a viable organ transplanted if that organ was

removed from somebody on cardiopulmonary support, as opposed to turning the cardiopulmonary support off, letting that person “so-called die,” and then having to engage in the extraction of that organ and the transplant of that organ. Perhaps you could tell the committee about the viability of that organ being transplanted into somebody who simply does not have an option in terms of receiving that organ, who needs it to live (Canada, 1999a).

The Member of Parliament, like the transplant physician in 1972 and in multitudes of examples demonstrate that the way in which transplantation objectifies is through a gaze upon some patients—potential donors – *for* potential recipients.

In conducting research for this study nine years later, I was reminded of my concept of the *double gaze*.¹⁸ The TGLN hospital Organ and Tissue Coordinator I interviewed exemplified the kind of orientation in thinking found in the above examples. She told me,

Often people say to me sometimes “you have a really crummy job because you deal with death all the time.” And my response to them is “I have an amazing job.” Because I can’t prevent the death right? [But] where else get do you go to bed at night and say “phew, you know what. I’ve just given life to four or five people.” And that’s amazing (OPO 4).

In maintaining a presence, facilitating donations and performing acts of gratitude to staff in the ICU and CCU, she saw herself as representative of all the potential recipients waiting for a deceased donor organ, unable to be present themselves. She objectified by ‘seeing’ ‘the medicine,’ as it were, in the dying patient. To perform her work, it was less the dying patient than the potential recipient who was upmost in her mind as she asked families for consent, and, ensured nurses and doctors reported potential donors to TGLN and performed the “donor maintenance” medical work.¹⁹

¹⁸ This concept played an insignificant part in the overall argument of my earlier research in 2001.

¹⁹ She even completed the Maussian tripartite circle of gift-giving by sending a thank you letter the donor family six months later and regularly bringing donuts to staff to show that she “gave” not only “took,” and occasionally bringing in an organ recipient as living proof of the impact of their work “making ‘medicine’.”

In my view, the mediated-by-intermediaries tension between the needs of recipients and donors in organ transplantation can be described as a *double gaze* in instances of looking at dying patients classified as potential donors, and, living persons undergoing donor evaluation. *Double gaze* fits these circumstance where medical professionals must “gaze” upon potential donors as subjects, asking “is death immanent” or “what is the likely impact of a nephrectomy on her/his health?” and as objects, asking “do tests show the kidney to be of value to the potential recipient?”²⁰ The weakness in the term *double gaze* is that it does not capture the reason for objectification, however desirable, which is to alleviate the suffering of potential recipients. It also conveys balance which I have argued is not the case. For this reason, I shifted from *double gaze* to recipient “gaze” or “centrism” as an orientation in thinking and acting towards one side of the equation.

In another contemporary example, in 2007, a leading anti-transplant abuse advocate, Dr. Francis Delmonico employs the same idea I pinpointed, but in a narrow sense in condemning evidence revealing transplant abuse in Pakistan.

Transplantation has become a tool, an instrument of brokers and hospitals and physicians and countries to make money by exploiting its poor. Money is dictating transplantation practices rationalized by *a recipient focus* that conveys a stark approach: satisfy the demand of the recipient at the cheapest cost, and dispense with the donor by a quick fix via the cheapest cash payment (Francis L Delmonico, 2007: 924, emphasis added).

My current findings reveal, however, consistent with my previous findings, that transplant practices, “rationalized by *a recipient focus*,” are not a function of money, nor unique to cases of

²⁰ The difference is that in living donation the potential donor is not already a patient. Asserting the subject status of living donors (and of prisoner’s in China) – where the donor is the person that matters – is, in fact, as we see in Chapter 7, the primary goal of the campaign against transplant abuse. It is also, in my analysis, a challenge at a systemic level in altruistic donation.

transplant abuse. Rather—and this is the point—it is a characteristic of the therapeutic modality itself. Altruistic kidney exchange does not happen without a recipient focus either, especially without, as stated above, *constantly reminding physicians of the needs of other patients*. The difference between legitimate and illegitimate transplantation lies not in the recipient focus, per se, as this characteristic is always there but in the degree of this focus and tempering this focus by limits on the extraction of organs, primarily by the assertion of donor protection.

Thus, recipient-centrism is an orientation that can inform behaviour of any and all parties involved, *not* an inherent characteristic of recipients (in response to Cara Kierans' critique of Scheper-Hughes in chapter one). Many potential recipients are so donor protective that they do not ask friends and relatives for a kidney. This was the case with two of my interviewees. Family members intervened in Elaine's case and her sister eventually donated to her. In Kelly's case, two friends offered but neither were found eligible. And she rejected offers to help her arrange to buy a kidney in India. Instead she waits on the deceased donor list. It is less at the individual level, however, that this study is concerned with than the mezzo-level of intermediaries. The question is where do intermediaries stand along this continuum? Rules guide practice but can, and are, pushed.

My vision is therefore of a continuum of relative interests, with recipient interests at one end and donor interests at the other. It is through the tension in meeting shared interests in renal function—mediated, importantly, by intermediaries—that organs become available and donors come into being. Having a language of relationality, tension, recipient-centrism and donor protection enables analyses of the demarcations made by rules that cut through different interests to allow some exchanges to proceed and others not.

3.2.2 Structurally Embedded

For some time, the need to provide organs has stood firmly as a moral imperative. In my previous study, I found that this imperative developed after the advent of cyclosporine, especially through the 1990s. In turning to this period, 2000-2014, I found that the ‘discourse of donation’ documented in chapter 5 to repeat and extend the position of transplantation understood as organ donation such that it remains an unquestioned, unmitigated good. What anchors the strength of this moral position, articulated in the discourse, is recipient-centrism: the ongoing call for greater consideration of potential recipients.

Importantly, the directional knowledge of recipient-centrism is not only ideational, it is embedded in the mandate and practices of intermediary organizations that do the work of creating an organ supply. The mandate of Ontario’s Organ Procurement Organization, Trillium Gift of Life Network, is,

...to create transformational life-saving or life-enhancing opportunities for people needing organs or tissue. We do this by not only managing the organ and tissue donation, recovery and allocation system, but also by promoting a culture of donation in the province.

As we see in chapter 5, the ‘culture of donation’ is the vision identified above that transplant surgeons articulated in 1969: the forming linkages to emergency wards *to constantly remind physicians of the needs of other patients* and securing legal consent in life. This is less obvious in the mandate of the federal Canadian Council on Donation and Transplantation (CCDT), which existed from 2003-2007 with a “mandate to provide advice directly to the Conference of Deputy Ministers of Health related to a coordinated strategy for improving donation and transplantation in Canada” (CCDT, 2005: 2). And, similarly when the activities of this organization were reallocated in 2008 to the national blood agency, Canadian Blood Services. Again, the mandate is to “...develop a plan for an integrated organ and tissue donation and transplantation system”. Implied

is the need for an improved and integrated national donation and transplantation system, the goal of which is to increase the number of organs for potential recipients. Searching for data on donors also proved challenging for reasons of recipient-centrism. I open the next chapter by detailing the imbalance of information on recipients versus donors which arises from the historical focus on treating illness.

As a point I return to in the conclusion, the intermediary organization of organ procurement organizations such as TGLN can be thought of as government departments of body parts. Especially since becoming a priority in 2000 in Ontario, creating kidneys as a resource to heal the ill is an accepted and expected job of government. For all of the lives saved and improved as a result, the mandate is narrow. It starts once the threshold of the hospital is crossed and not before other than to raise awareness and educate the public to secure advanced consent to organ donation. It is also supply-focussed, excluding the strategy of making more organs available by reducing demand. Moreover, I argue that the structural embedding of recipient-centrism is one source, among several, of the kind of gross dissociation from alienability and relationality that concerns me and other observers. Considerations of the societal level routes that connect donors to recipients at the point of kidney exchange are excluded from view. As quoted in the introduction, Lesley Sharp (2014) captures this succinctly: “...concerns may *focus nearly exclusively on the needs of dying patients* yet not, for instance, on broader health disparities that shape the calculus of heart or lung disease, liver failure, or diabetes, on the circumstances of donors’ sudden or even violent deaths.” On the demand side, how a middle-aged First Nations man like former Member of the Manitoba Legislature, The Honourable Elijah Harper, contracted End-Stage Kidney Disease. And, on the supply side, the kinds of violence, intentional and unintentional, that oftentimes results in a potential deceased donor is equally beyond view.

Recipient-centrism is also imbued in the meanings used to describe medical practice. For example, a 2003 CCDT medical guideline on Severe Brain Injury to Neurological Determination of Death aimed to fix a problem that, “inconsistencies in the identification and management of patients with severe brain injury who may evolve to brain death limit the number of organs available for transplant.” Such guidelines aim to make potential donors visible *for* potential recipients. Yet, as we see in the ‘discourse of donation’ in chapter 5, actions undertaken for recipients become obscured over the 2000-2014 time period by the language of a desire to donate. For example, DCD is introduced to hospitals as positive because it, “provides the family of patients who do not meet the criteria for donation after neurological death the option of honouring a loved one’s wish” (TGLN, 2005). Organ donation is for the family and the donor, not the recipient.

The concept of recipient-centrism and my interpretation of this ideational orientation embedded in practices and structures provides an explanation for the phenomenon of ‘structured forgetting’ identified in the introduction. Potential donors come into view only once they are classified as potential donors. There is nonetheless a tension, which we see in the chapters that follow, especially on living donation, whereby recipient-centrism is countered by donor protection.

It is important to recognize that conversion from potential to actual donors is not always the outcome for reasons of eligibility and system performance. Deceased and living potential donors are regularly deemed ineligible when they fail to meet donor eligibility criteria and/or when a step in the multiple sequence of procedures in deceased donation fails to occur. Two examples conveyed to me by key informants include: when a TGLN Donor Co-Ordinator is unable to get to the hospital to ask for consent before the mechanical ventilator sustaining the vitality of the organs is turned off; and a systemic problem of operating rooms not being available in time (OPO 1). Further, donor eligibility criteria enable by limiting by demarking the line between recipient-

centrism and donor protection. As we see in chapter 7 on living donors, medical guidelines started to assert that “donor autonomy does not overrule medical judgement and decision-making” (TTS, 2004: 492). As I learned in my interviews, Ontario transplant programs started to assert this policy position upfront as a means to manage aggressive potential donors determined to give their kidney to their loved one even when declared medically ineligible (DT 2). Transplanters hold a recipient-centric outlook but also temper this orientation by asserting donor protection.

3.3 Conclusion

To recap, the purpose of analyzing five necessary and enabling dimensions is to recognize the embeddedness of organ exchange in any society and discern its complexity. First, investment is a choice and there are vested interests. Second, medical authority and jurisdiction means transplantation is subject to gains and losses of trust in medicine *writ large* and to competing forms of authority (e.g. from religion to alternative health movements). Third, transplantation is expansionist yet constrained by immunological compatibility and immunosuppression and is dependent upon organ supply.²¹ Multiple demand sources put pressure on increasing organ supply which is framed – as we see further in Chapter 5 – by a discourse of organ shortage. And, fourth and fifth, are ‘pools and rules’ by which I argue, in sum, that rules enable by setting limits to protect donors and all parties from the threat that kidneys are valued ahead of persons. As boundary-work, the lines drawn by ‘pliable’ and ‘rigid’ rules determine the scope and characteristics of pools of potential donors. Chapter 6 illustrates how key informants raised issues

²¹ As we see in the next chapter, only blood and zero donor-antibody matches work between donors and recipients accompanied by varying degrees of immunosuppression.

of alienation that are invisible or marginal in standard understandings of transplantation as organ donation.

If I am right that organs have acquired a value that poses a threat of valuing organs ahead of persons, and that transplantation is expansive, it would follow that kidney exchange revolves around managing this threat. When we look at the rise of forms of living donor protection in chapter 7, the threat does take centre stage. However, the rules of altruism are claimed to remove the threat such that it is not a problem; it is taken care of by the rules, especially the prohibition of monetary exchange and requiring separate donor and recipient teams.²² The central question then, especially given TGLN's mandate in 2000 to double the deceased donor rate, is whether it is possible to raise the volume of kidneys to meet demand within the original rules? In other words, is this goal possible without pushing these boundaries regarding altruism and alienability? We see in the ensuing chapters that the answer to this question for both deceased and living donation is no: in changing the rules, the intermediaries (transplant physicians and organ procurement organization staff) determined the boundaries to be too restrictive. But since it was the pliable rules – not the rigid rules – that have changed (with one exception for living donation), there was no need to engage the public at all and certainly not at a level required for legislative change.

Returning to the introductory story about kidney exchange in Ontario, in both deceased and living donation, starting around 2006, the boundaries established by the foundational rules are pushed. The pools of potential dying and living donors expand as a result of broadening the pliable rules in medical guidelines: more people are counted as dead and the balance of beneficence and

²² We see that twice when controversies over what is death 'flare up' that this claim of threat safely contained is asserted repeatedly as a defense, especially the 'separate teams' rule.

non-maleficence is interpreted more liberally to allow more living people to donate. As we see in chapter 8, the rigid rule prohibiting sales is also interpreted narrowly in order to start paying living donors for their expenses.

I show in Chapters 4 through 8 that the orientation of recipient-centrism is deeply embedded in altruistic organ exchange in Ontario. Over a close to forty year period, this system has provided over 12,000 Ontarians with kidneys that removed them from dialysis and saved their lives. In the conclusion I acknowledge broader questions that require research beyond the scope of this study such as the extent to which recipient-centrism is needed.

Chapter 4 Ontario's Recipients, Donors and Intermediaries

Before turning to the specifics of the two systems for generating kidneys from the dying and living, this chapter adds depth and place to the previous one by extending our broad outlook another step. Here we move from theorizing to a quantitative description of how kidneys are exchanged in Ontario retaining a view of both deceased donation and living donation.

This chapter asks the question: who needs and receives kidneys, and, who gives them in Ontario? Although the answers are largely descriptive, aspects of the argument of the thesis are evident. In particular, this chapter quantitatively illustrates the broadening donor eligibility criteria that start in 2006. The positive impact of Donation after Cardiocirculatory Death (DCD) raising the deceased donor rate is clear. The impact of living donor changes addressed in chapter 8 are less evident but this may be attributed to differences in data collection.

I claim that what follows is a contribution to scholarship on body part exchange for two reasons. Not since Richard Titmuss's (1970) account of blood donors has there been a comprehensive jurisdictionally-grounded picture of donors of any body part. Also, while still insufficient, the qualitative details provided below are original in compiling information from several sources. This makes the donor information that follows unique since the full-spectrum of exchange relations revealed and the causes of donors' deaths are excluded from standard public reports.

I begin by noting the imbalance in data available on recipients and donors which I claim is another example of the way in which recipient-centrism is embedded in organizational structures, this time the registries that gather statistics on transplantation. I then turn to explain and detail who needs kidneys by describing End-Stage Renal Disease and the treatment options of dialysis and

transplantation. How the success of transplantation rests on the possibilities and constraints of immunological matching/suppression as well as donor renal quality is then documented. From whom did the kidneys come? The chapter then looks at Ontario's donors and organ providers outside Canada. Here I present an original profile over 44 years, of the 8,151 kidney donors (4,616 deceased and 3,507 living donors) who provided 12,761 kidneys to ESRD patients between 1966 and 2010 to Ontarians.²³ The last section initiates the split that follows by detailing the differences between the two systems in Ontario of deceased donation *community altruism* and living donation *intimate altruism*. This sets the stage for chapters 5 and 6 specifically addressing the former and chapters 7 and 8 specifically addressing the latter.

4.1 The Recipient-Donor Imbalance Begins with Data Collection

What is publicly known about Ontario's kidney donors is minimal. Data on kidney transplantation evolved from and therefore still reflects nephrologists' efforts to monitor incidence and prevalence and improve the treatment of renal disease. A Canadian Renal Failure Registry was established in the 1960 and produced annual reports until 1980 when this role was assumed by the Canadian Organ Replacement Register which produces an annual report called, "Treatment of End-Stage Organ Failure in Canada."²⁴ In the early series, the focus on kidney disease results in the only record of donors being numbers, categorized as cadaveric donors or live donors. The current

²³ Figure 2 in section 2.4b, below, shows activity at Ontario transplant centres for a total of 8,123 donors (4,616 deceased donors and 3,507 live donors) to which I add 28 kidney providers whose donor nephrectomies took place outside Canada.

²⁴ The Canadian Renal Failure Registry was funded by the Kidney Foundation of Canada. The Canadian Organ Replacement Register is housed within the Canadian Institute for Health Information, an arms-length not-for-profit agency of the federal government mandated to monitor the performance of the provincially-delivered health care system. Although voluntary participation in Canadian Organ Replacement Registry is high, there are no enforceable reporting requirements.

Registry is similarly transplant recipient-focussed. Organ donors come into view only as ‘medicine,’ being one type (living) or the other (deceased). The pathway of donors is excluded. There are, however, two reports, one published in 2002 and the other in 2009 of note.

As in all Canadian Organ Replacement Register reports, data are national in scope and prioritize regional and provincial comparison. The 2002 report includes cadaveric donor causes of death from 1992-2000; this is not repeated in any subsequent reports. The 2009 report is an exception. Titled, “Organ Donor Activity in Canada, 1999-2008,” this is the only report during the period under study (2000-2014) dedicated to presenting data on donors. In it living and deceased donors are compared overwhelmingly by region and province. Isolated data are provided, however, on the relationship of donors to recipients and to whom live kidneys go, by age and gender.

While the existing data provides some insight, the End-Stage Renal Disease patient focus leaves many questions regarding donors unanswered. Other than the 2009 report, there is almost no publicly available information on who donors are, how they become donors and any changes in donor eligibility criteria other than a consistent distinguishing of deceased donors by death determination.²⁵ Most important is the absence of data on the size of the pool of deceased donors and on living donor health outcomes. One shift, however, around 2012, is the addition of potential deceased donors in one on-line dataset publicly available at the Canadian Organ Replacement Register website (CORR, 2014e).

The structural explanation for the paucity of data on donors is straightforward. The Canadian Organ Replacement Register is a national database managed by the Canadian Institute for Health Information. The mandate is to “record and analyze the level of activity and outcomes of vital

²⁵ Whether any donor nephrectomies have resulted in death and rates of associated morbidity is unknown.

organ transplantation and renal dialysis activities” (CORR, 2014c). This focus does not generate a place for monitoring donors; “outcomes” refers to recipients and does not extend to living donors. Further, the members of the Registry include physicians and surgeons from four nephrology and transplantation professional organizations, all of whom serve potential and actual recipients.²⁶

4.2 Therapeutic Options for Treating End-Stage Renal Disease

Donors are not donors without the people who need their kidneys: potential recipients. Thus, to understand kidney donors and kidney exchange, some basic knowledge about End-Stage Renal Disease (ESRD), treatment options and transplantation as a therapeutic modality are necessary. Kidney disease is a chronic illness that is caused by any condition that damages the blood vessels, the two most common being diabetes and hypertension, both of which are preventable. Other leading causes are polycystic kidney disease, pyelonephritis, and glomerulonephritis which are inherited. Chronic kidney disease is treated with medication but often progresses to a level of kidney function so low that patients are re-classified as having End-Stage Renal Disease. This point signals the necessity to initiate renal replacement therapy for which there are two modes: dialysis and transplantation. Both modalities enable patients with severe kidney failure to continue to live, their kidney function replaced by either the work of a machine or a new, third kidney.

Systematic data collection on the ESRD population, including treatment patterns and outcomes, date back at least 30 years in Ontario. As of December 31, 2007, there were 35,265 people in Canada being treated for ESRD, with 40% living with a functioning kidney transplant

²⁶ Members include the Canadian Society of Nephrology, the Canadian Society of Transplantation, the Canadian Association of Transplantation and the Canadian Association of Nephrology Nurses and Technicians. The purpose of the Register is also to provide information to hospital administrators, government officials, researchers and the Kidney Foundation of Canada.

and 60% receiving dialysis. Most ESRD patients are between the ages of forty and fifty-nine, and the trend is toward increasingly older people (Canadian Institute for Health Information, 2009: 18). Patients are also about 60% male. A CORR report confirms that “as the Canadian population ages, so does the group of patients receiving a kidney transplant.” Over the period of 1999 to 2008, the proportion of recipients older than age sixty receiving a transplant from a deceased donor has risen from 21% to 35%. A similar trend is observed for living-donor transplants, rising from 12% to 19% (Canadian Institute for Health Information, 2009: 17). One transplant centre informed me that their oldest recipient was over eighty years of age. This data demonstrates that the failure of organs is a function of an aging society. However, medical advancements may also be a contributing factor. One expert noted that demand is on the rise because people now survive diseases and surgeries that are “hard on the kidneys” (DT4). Thus treating one condition leads to the need to treat another by replacing a kidney.

As one of my interviewees conveyed, up to 70% of dialysis patients are ineligible for transplantation largely due to comorbidities (DT4). While lung and liver transplant candidates have no mechanical option, a person can survive on dialysis for decades. Dialysis is nonetheless berated as a burden. It is time consuming and patients feel ill often all the time. Yet, in Ontario, 10% of patients choose dialysis—“the devil they know”—over one they do not, transplantation (Tx6). A recent post captured what a transplant candidate—who longs for a kidney—articulated as the “trade-offs.”

Yes, my dialysis schedule (20 hours a week) is a huge *compromise in my quality of life*, TIME-WISE, but I do feel *really well*. My problem isn't the new kidney itself. My problem is the *side-effects of the antirejection medications I will be taking in order for my body to accept this foreign organ*. The last time I had a kidney transplant my biggest problem with the antirejection medications was *constant upset stomach*. (I had a kidney before for 13 years). A *“losing weight, dehydrated” level of upset stomach. Painful cramps. Not good*. In the back of my

mind I am *afraid that it will be a trade off of quality of life factors*. I will have 30 hours a week of my life back—in not having to do dialysis but . . . *will a majority of my time be compromised with feeling ill with side-effects?* I know that sounds really ungrateful of me but it's a *real consideration*. (K. N. Smith, 2014 author's emphasis)

This statement also clarifies that organ transplantation, as a form of therapy, is not just an organ; it is a new organ plus a daily drug regime.

In the public realm, transplantation is heralded as a miracle. Yet some transplant centres emphasize that it remains a form of treatment, not a cure. Far from their idealized abstractions in the media as no longer ill patients, transplant recipients continue to suffer even if the quality and degree of suffering shifts and lowers and they are liberated from the ties and tolls of dialysis (Kierans, 2011). Immunosuppression drugs carry a risk of causing cancer and other negative side effects. Recipients are also more vulnerable to infections and therefore must avoid exposure to germs. As in the case of Karen Nicole Smith, quoted above, patients transplanted early in life often cycle through transplantation to dialysis to transplantation since transplanted organs last 10 years on average. Re-transplants constitute approximately 10% of annual transplants in Ontario. There were 10,207 kidney transplants in Canada between 1998 and 2007, of which 12% were re-transplants (Canadian Institute for Health Information, 2009: 16). Thus, kidney transplantation works but works conditionally—only from blood-type compatible donors, only accompanied by immunosuppression, only so long, and, better from some donors over others.

The other mode of renal replacement therapy is dialysis, the evolution, benefits and constraints of which are useful to keep in mind. There are two types, hemodialysis and peritoneal dialysis, with an expanding array of delivery options. Hemodialysis takes four hours at least three times a week and is offered in-hospital (and one Toronto hospital offers a nocturnal program), and, as self-dialysis at home, including an at-home nocturnal option (as long as clean water, a sterile

environment and electricity are secure).²⁷ Peritoneal dialysis is more mobile, allowing patients to travel with their provisions and self-treat wherever they are, four to five times a day. While dialysis is emphasized to be expensive and is portrayed as universal in quality, its provision may vary by place and funding model. To reduce the high cost of dialysis, the Ontario government prioritizes kidney transplantation by granting unlimited special funding of every transplant. This ensures transplants are not postponed into a new fiscal year when hospital budgets are strained. One key informant interviewed for this study conveyed that this policy effectively creates an incentive for nephrology units to transplant as many patients as possible to alleviate the cost of their dialysis case load which must be funded out of the annual global budget (Tx7).

Unless a donor comes forward to offer a kidney, patients whose kidneys are failing must start dialysis or they will die. Nephrologists prepare patients and their families for this end-stage moment by alerting patients and their families that the time has come for a donor to step forward or preparations will be made to initiate dialysis. As we see below, for patients who meet transplant eligibility criteria, a new kidney from a live donor is considered the best course of treatment, ideally pre-empting the need to initiate dialysis. The pressing question for these individuals is who is in their pool of potential live donors.

4.2.1 Immunological Compatibility

Transplantation works by fooling the immune system into accepting the foreign organ as self; thus, the techniques of matching and immune suppression are crucial to the success of the therapeutic modality. In Lawrence Cohen's (2005) view, the rise in medical reliance on tissue

²⁷ At-home dialysis of either type is Ontario's preferred delivery option as it is the most cost-effective.

exchange is schematically represented by three technical shifts: surgical techniques; immunological techniques recognizing degrees of relatedness; and, immunosuppressant drugs. Whereas the need for blood and tissue matching led to relying on deceased donation, “the suppression of difference, made possible both the globalization of the transplant operation and the emergence of multiple bioavailable populations” (L. Cohen, 2005: 84, 85). His list of the “bioavailable” includes: donors who give a loving, charitable, dependent or anxious gift, commoditized sale, or, authoritarian or covert seizure. With immunosuppression, renal transplantation is less dependent on finding matches within a large population, it can decentralize. This makes it feasible for Ontarians to purchase a kidney from a stranger in South Asia. However, research on tissue compatibility over the last decade has reasserted the place of matching in avoiding organ rejection while extending the size of donor pools by accepting less healthy kidneys. Cohen’s interpretation can be updated, then, to reflect that the immunological matching-suppression interaction contributes to a mix of rigid and flexible requirements and a hierarchy of value making some kidneys preferable to others.²⁸

As illustrated in Tables 1, and 2 during the period of 2000-2014, kidneys must match by blood and the absence of donor antibodies. Table 6 reflects the flexible requirements alongside additional factors of renal quality and timing that make a kidney and its receipt of greater or less benefit to the recipient.

Table 6 *Matching Kidneys*

Absolute	Flexible
Blood type compatibility	HLA Antigen match
No donor-specific antibodies*	Renal function

²⁸ I make this analytical claim knowing that it is temporary. The next biomedical development will again shift what we can say about kidney value.

*Lymphocyte crossmatch compatibility test

Table 7 Blood Type Compatibility

Recipient blood type	Donor blood type
O,A,B,AB	O
A	A,O
B	B,O
AB	AB

Table 8 Biomedical Kidney Preference

Highest to Lowest, After Blood-Type and Antibody Crossmatch Compatibility

Quality	Probability of Tissue Compatibility		Receipt Timing	Time in Transit	Renal Function
High	<i>Live Donor</i> Siblings Parents Children Other biologically related kin (cousins, aunts/uncles) Non- biologically related	6 HLA Antigen match	Short	Pre-empting dialysis	Standard Criteria Donor Compromised (From a Medically Marginal/ Complex Living Donor or Expanded Criteria Deceased Donor
Low	<i>Deceased Donor</i>	0 HLA antigen match	Long	After dialysis	

As we can see, above, the donors of choice are: living donors; ideally a sibling who is a standard criteria donor and is available to donate prior to the commencement of dialysis. Siblings are the most likely to be a perfect match by sharing all six HLA antigens. Other biologically related family members are next, followed by further kin. If family members are unavailable, everyone non-genetically related is equal, from a biological point of view; immunosuppression drugs will be relied on to suppress antigen difference.

Missing from Tables 6, 7 and 8, however, are two additional categories. There are patients who are designated “highly sensitized,” meaning that they have more antibodies and will be more difficult to match. My research found that transplant centres were conscientious and sought ways

to alleviate inequalities in wait times that arose as a result of biological factors such as sensitization. Further, there is a relatively new technique for mismatched living donor pairs called “desensitization.” This is a protocol whereby potential recipients undergo a series of procedures to rid their body of donor-specific antibodies. This removes the absolute tissue incompatibility barrier to allow donor-recipient dyads to proceed with organ donation and transplantation. Desensitization protocols became available in Ontario at a few transplant centres only within the last three years, and the degree to which potential recipients can be desensitized varies by case and by centre.

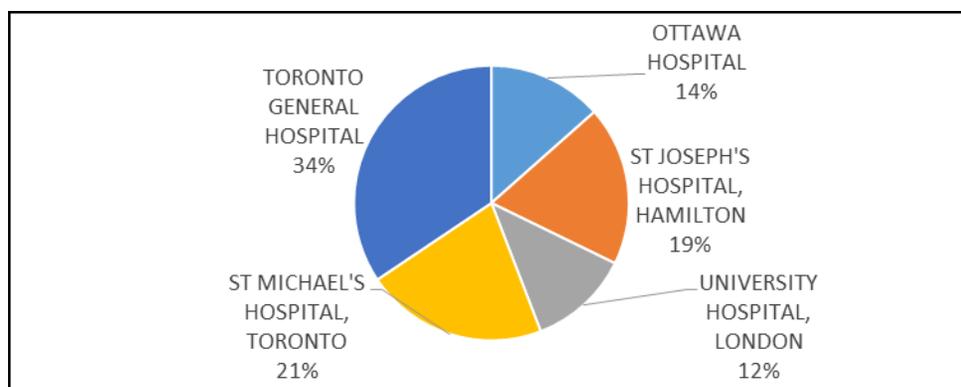
We see in the last three columns of Table 8 that influential factors beyond immunology are matters of timing and organ quality. Advanced preparation, especially blood and tissue matching, possible with live donation is preferable, plus it reduces the time the kidney is *ex vivo*. Notably, in Ontario, the public policy on kidney allocation developed by the nephrology community requires End-Stage Renal Disease patients to initiate dialysis prior to being listed for a deceased donor. Disallowing anyone from qualifying for what is called pre-emptive transplantation (pre-empting dialysis) is one of many measures intended to ensure equity among transplant candidates waiting for deceased donor organs. The last column reflects one type of eligibility criteria boundary pushing that aims to make more kidneys available. Deceased donors classified as “expanded criteria donors” are usually from donors aged 60 years or older or over 50 with reduced renal function due to a medical condition such as hypertension. The parallel category, called “medically complex living donors,” are donors with conditions such as well-controlled hypertension, mild obesity or stable psychiatric disorders.

4.3 Ontario’s Transplant Centres

As noted in the introduction, in 2000, the provincial government of Ontario made a very public and decisive move in the field of transplantation by setting an ambitious goal to double the deceased donor rate within five years and devoting significant public monies into a new organ procurement organization, Trillium Gift of Life Network (TGLN). At 7 million dollars in 2002-2003, the size of the TGLN budget set the province apart from the rest of the country and put it on par with jurisdictions in the United States such as the city of Philadelphia. If raising deceased donor rates depended on financial investment, the numbers ought to rise here. However, as we see below, annual rates remained stable and rose only after the pliable rules of deceased donor eligibility were changed to include Donation after Cardiocirculatory Death.

As the largest province, there are seven renal transplant centres: three in Toronto (one for children, two for adults) and one in each of the province's four large cities: London, Ottawa, Hamilton, and Kingston. All centres perform deceased donation. Since 2004, six of the seven have live donor programs.²⁹ Figure 1 shows the differences in the size of living donor programs at each centre.

Figure 1 *Live Kidney Donor Transplants in Ontario, Volume by Adult Living Donor Program, 1966 to 2011.*



²⁹ The centre at Kingston General Hospital performed live donor transplants starting in 1978 and ceasing in 2003.

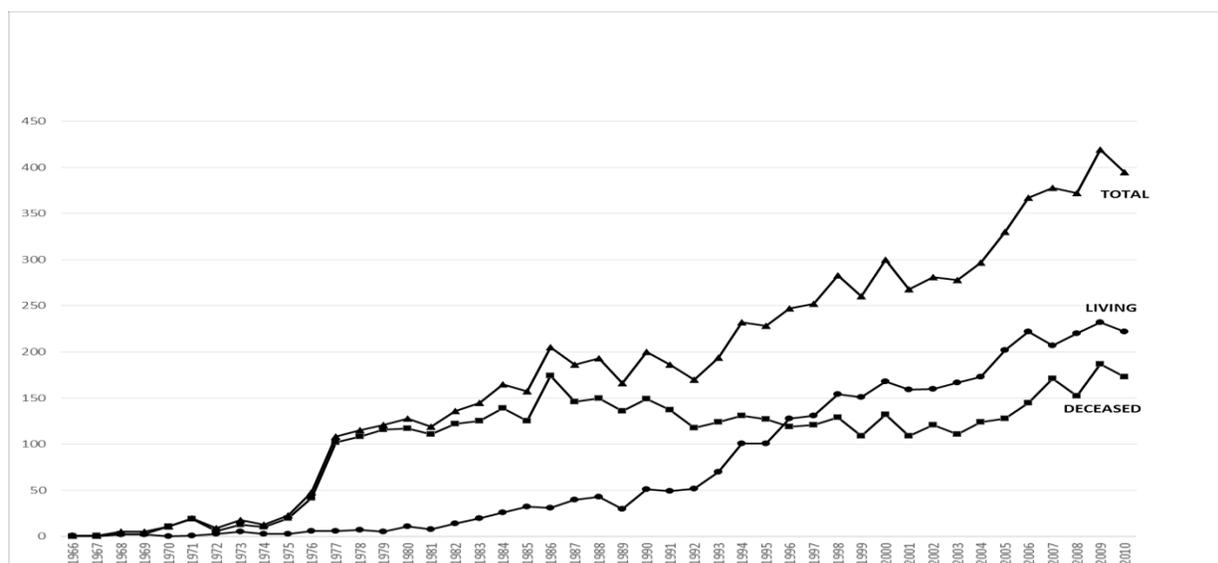
Note. Data from TGLN, TOTAL database, retrieved April 8, 2011. N = 3,507

As a cumulative average over the period of 1966 to 2011, the volume of living donor transplants as a percentage of all transplants varies from Toronto General Hospital at the high end at 34% to University Hospital in London at 12%.

4.4 Ontario's Donors

What is readily available in annual reports and on-line, albeit reaching only a decade back, is the volume of deceased donors and living donors. In order to address questions about Ontario's donors that arise in later chapters, the analysis that follows draws on provincial data acquired upon request and, for living donation upon other sources of data, for a longer-term and fuller profile of these populations. Figure 2 illustrates the long-term comparison between deceased and live kidney donors in Ontario from 1966-2010.

Figure 2 *Kidney Donor Trends in Ontario, Deceased and Living, 1966-2010*



Notes: Total Donors = 8,123 (triangle dots), Deceased = 4,616 (square dots), Living = 3,507 (circle dots). Reported by calendar year; Includes imported kidneys from out-of-province deceased donors. *Source:* TGLN, TOTAL database, data extracted on May 13, 2011.

While the total number of donors rises to around 400 over the 50 year period, living donors start to exceed deceased donors in 1996. The pattern of deceased donors is addressed below followed by an analysis of living donor trends in Ontario.

4.4.1 Ontario's Deceased Kidney Donors

The trend line in Figure 2 for deceased donation shows a jump from 48 deceased donors in 1976 to 108 in 1977 after which deceased donation remains steady, at an average of approximately 140 donors/year, rising to 187 in 2009 at the end of the period. The annual numbers vary considerably within a narrow range. Given that TGLN's success is measured almost entirely on achieving a targeted number of deceased donors per year, the figures during their tenure are worth a closer look.³⁰

First, when we compare their success to previous decades, we can see in Figure 2, above, that the period of TGLN's operations, from 2002 to 2010, only moderately surpasses the success of the 1980s and 1990s in spite of \$7 to \$14 million in annual funding. Since data prior to TGLN's existent is not made readily available, the lack of impact by the organization that these numbers imply is not evident to the public.³¹ In chapter 6 we see an explanation for TGLN's weak impact that returns to the issue of dependence on the pool – and specifically on the size of the pool of potential deceased donors. As we see, this explanation counters the common and promoted view that consent and hospital efficacy will and can significantly increase the rate of deceased donation.

³⁰ Note that TGLN Annual Reports use the fiscal year, April 1 to March 31, as opposed to the calendar year data provided here.

³¹ Towards the end of the decade, the TGLN website includes a webpage showing a ten year history of deceased, living and out-of-province organ donors.

Table 9 Ontario's Deceased Kidney Donors, 2000-2010 by Death Determination

Death Determination	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total	Avg/Yr
Total (Figure 2)	132*	109	121	111	124	128*	145	171	152	187	173	1553	155.3
NDD (Brain)	132	109	121	111	124	128	141	154	124	152	140	1436	143.6
DCD (Heart)	-	-	-	-	-	-	4	17	28	35	33	117	23.4

Notes: The asterisks show the failure to double the annual rate from 2000 to 2005. The grey colour shows TGLN's period of tenure given that the organization became operational in 2002. The average deceased donors per year over the nine years of their tenure is 145.8 which is 5.8 donors per year above the average annual rate in the longer period of 1966 to 2010.

Source: TGLN, Total Database, data extracted on April 8, 2011.

When deceased donor eligibility criteria are held steady, counting only the brain dead (NDD for neurological determination of death), the rise in the total numbers of deceased donors is less impressive. There is nonetheless a spirit of success in Ontario. Recent studies found that "Ontario is the only province to demonstrate growth in deceased donor rates over the last decade (25% over the last four years [2006-2009]), which can be attributed primarily to the success of its DCD activity" (Hernandez-Alejandro et al., 2011). As mentioned above, DCD refers to death by cardiocirculatory determination, in other words, heart-based criteria as opposed to brain-based criteria. We see above that an additional 117 donors are added. Extending into the next year, between 2006 and April 8, 2011, there were an additional 239 kidney transplant surgeries from DCD deceased donors (TGLN, 2011).

Based on their own data, TGLN's improvement in the number of deceased donors based on brain death is marginal. Major improvement in the annual number of deceased donors comes only from changing the pliable rules of medical guidelines with respect to the diagnosis of death. Counting more people as dead at an earlier point in the process of dying expanded the pool of potential donors and converted more potentials into actual donors.

How did Ontario's kidney donors die? Appendix A shows the primary diagnosis that led to brain death (NDD), or, starting in 2006, Donation after Cardiocirculatory Death (DCD) for all deceased kidney donors from the earliest on record, 1967 to 2010. The legend orders the seventeen causes from highest to lowest. As a whole, this group of diagnoses belong to the umbrella category of Catastrophic Neurological Conditions. Most deceased donors died of spontaneous intracranial hemorrhage followed by motor vehicle accident, head trauma and anoxia/hypoxia. An advanced analysis, beyond the scope of this thesis, would take the additional step to identify the biomedical and societal conditions and causes that lead to the primary diagnoses for End-Stage Renal Disease transplant candidates (such as diabetes) and deceased kidney donors (such as head trauma). This would extend the lens even further outward from the donor-recipient point-of-contact that is the focal point of kidney exchange. An important question, beyond the scope of this study, that deserves investigation is whether marginalized people (for reasons such as socioeconomic status, housing security or racialization) are more likely to become potential recipients and potential donors.

4.4.1a Allocation

To whom did deceased donors' organs go? Allocation is a responsibility of the provincial OPO, TGLN. Here we see a tension between the intermediaries of the OPO and transplant centres. The promise to donors is that the patient in greatest need receives the donated organ(s). However, allocation can be organized at different geographic scales. Historically and throughout the 2000s, the practice in Ontario is for one kidney from a deceased donor to be kept in the region for the patient at the top of the local transplant centre list, and the other kidney would be offered to other centres. This means that five adult

deceased donor wait-lists for kidneys existed and the wait time for a kidney varied depending on where a patient lived in the province. This system did not match the public perception – promoted in TGLN organ donor campaigns (reviewed in the next chapter) – that organs belong to all Ontarians, equally, and access is at a provincial, not regional, level. TGLN held this view and sought to merge the five lists into one. In 2010 a senior staff member told me that this was a challenge because transplant centres had their own interests in mind:

We have a provincial committee for kidney allocation and for liver. Both met several times over the last year at our encouragement to move to a single list. We are making progress...it's a tough slog because there is concern from some of the smaller transplant programs that with a single list, they won't get as many donors. You know, Toronto has the biggest [wait] list, Toronto has the lowest donation rates. The fear from the other centres is that all the organs will come to Toronto. And, *there won't be enough transplant cases for viability of the other centres*. That's the biggest impediment to a single list. But, yes, we are working on it. (OPO 1, emphasis added)

This issue did not receive public attention other than one exposé report in the *Toronto Star* in 2006 titled, “Organ donations should go to those most in need” (Editor, 2006). But this controversy passed quickly. Highlights from the annual report of 2013/2014 celebrates a new allocation system that will be more equitable for Ontarians (TGLN, 2014a). However, the only details provided describe the same system as was in place which suggests that TGLN compromised on the goal of shifting deceased donor kidney allocation to a single-list provincial model. The lack of concern over allocation in Ontario stands in stark contrast to the United States where there are open controversies regarding the geographic distribution of deceased donor organs (see, for example, Davies, 2006; Koch, 2002; Zink & al, 2005). And, the discordant OPO – transplant centre relations in Ontario (and similar jurisdictions) are the kinds of intra-intermediary dynamics that flesh out the ways organizational gifts in Steiner's (2014) model (reviewed in chapter 2) are mediated.

4.4.2 *Ontario's Live Kidney Donors*

According to the provincial database, there were 3,507 live kidney donors from 1966 to 2010 who had surgery at an Ontario renal transplant centre (TGLN, 2011).³² We see in Figure 2 above that the annual number of living donors is very low until 1981. At this point, live donors rise continuously, surpassing deceased donors in 1996 and reaching over 200/year since 2005. If we look at this by comparing decades, in 1990 there were 51 live donors, in 2000 there were 168 live donors and in 2010 there were 222 live donors. This rise is reflected in the standard narrative developed in the early 2000s regarding living donation:

Living donation is an increasingly important source of organs for transplant—accounting for most of the increase in the number of donations over the last decade. Since 1992, living donations have increased by 254 percent compared to a three percent increase in cadaveric donations (donations from deceased donors) (TGLN, 2003).

However, counting by the number of transplant surgeries puts the two sources in better balance given that deceased donors generally yield two kidneys for every single kidney from a live donor. In Ontario, the percentage of live donors as a percentage of the total number of kidney transplants consistently hovers within a 10 percentage-point range, just below half, from 49% (2002/03) to 39% (2010/11) (CORR, 2013).

One question that Figure 2 prompts is why living donors continue to increase in numbers. One explanation offered by key informants was the improvement in nephrectomy surgery. As opposed to the original “open” or “plank” surgery used to remove the kidney, laparoscopic surgery

³² The first live donor kidney transplant in Ontario was in 1958.

has a lesser impact on the donor. Post-operative recovery time is faster and three small scars remain as opposed to a long slash across the mid-section.

Who are Ontario's organ donors? As mentioned above, publicly available information gives some insight but an incomplete picture of the variety and nature of social relationships between donors and recipients and intermediaries. The numbers above, in Figure 2, count only people who donated at Ontario hospitals or transplant centres. It does not count the kidney exchanges with Ontarian recipients that occur outside Canada. There is evidence, for example, of 28 unrelated persons (12 in South Asia, five in East Asia, one in Southeast Asia, four in the Middle East and six unknown) who have provided a kidney in a commercial transaction to an Ontarian between 1998 and 2005 (G.V. Ramesh Prasad et al., 2006).³³ The total number is likely higher over a longer time period, assuming similar numbers held at least the other transplant centre in Toronto and given that by 2011, 10% of British Columbia recipients have kidneys from commercial transactions in other countries (J. Gill et al., 2011). Of the 28, five of these kidney providers are from East Asia. Based on international evidence, they are likely deceased donors from China. The remainder are likely living donors. Our geographic and conceptual imaginary of Ontario's kidney donor population is therefore an international one.

The other international dimension to Ontario's donor population (invisible in the related and unrelated donor categories below) are the number of donors who travel from other countries to donate to Ontarians at Ontario transplant centres. There is a concern for all out-of-country

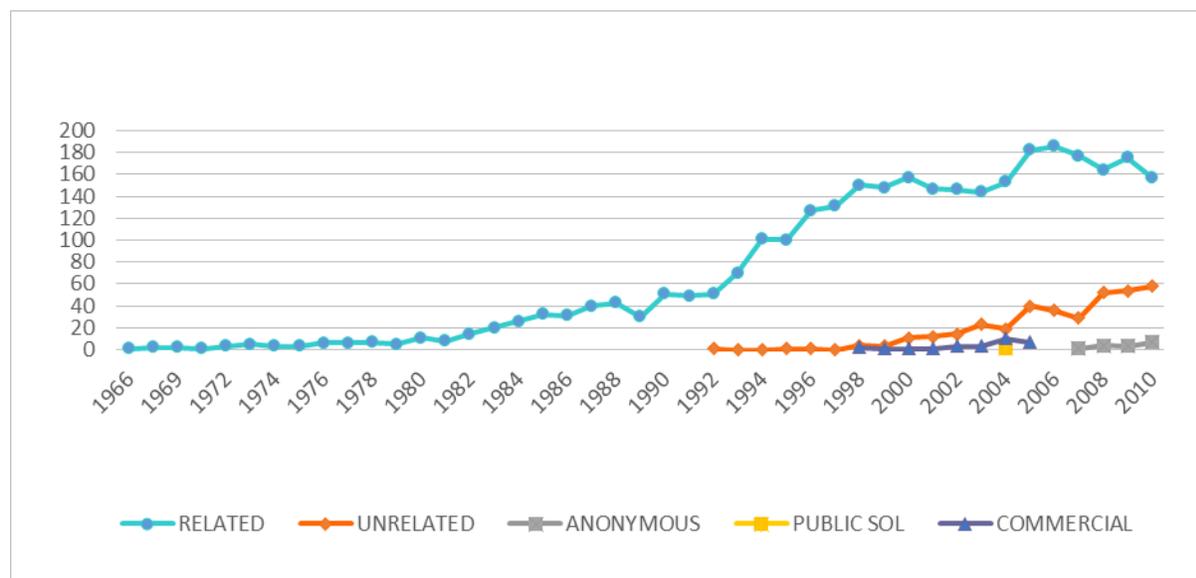
³³ This article is the only published evidence of the number of Ontario renal transplant patients who underwent a commercial transaction to acquire a kidney outside Canada. 28 is the number of patients identified on page 1133 of the article. This number is likely an underestimate. It is not based on medical claims. Canadian provincial health insurance plans do not reimburse transplant patients who have surgery outside the country. This figure is of the number of people whom nephrologists at St. Michael's Hospital in Toronto became aware of after they presented at the hospital in need of post-operative medical care from January 1, 1998 to December 31, 2005.

donors which is postoperative and long term health care coverage after their nephrectomy. And, as we see in chapter 8, unrelated donors who travel from another country to Ontario to donate are regarded with suspicion by donor teams who fear these donor-recipient relations are more likely to entail monetary exchange.

To fill out the paucity in public knowledge of living donors, Figure 3 compiles data from a few sources, including the ones cited above, to illustrate a broader profile of what is known about the proportion of donors to Ontarians over time by social category. Added to provincial data of the simple three categories of altruistic related, unrelated and anonymous, is one public case of public solicitation, in 2004 (Oad, 2004),³⁴ and data from the research article noted above documenting 28 recipients (suggesting 28 donors) who purchased kidneys outside Canada as part of a commercial transaction (G.V. Ramesh Prasad et al., 2006). These additions provide a broader picture of the donor population even if only four of five categories are performed at Ontario renal transplant centres.

³⁴ I subtracted one count from the unrelated category to assign it to this category.

Figure 3 Ontario's Living Kidney Donors, by Type, 1966–2010.



Notes. Public Sol = public solicitation.

Sources: TGLN, TOTAL database, extracted on December 8, 2010 and May 13, 2011; Oad, J. (2004); Prasad, Shukla, Huang, Honey, & Zaltzman (2006).

In looking at the proportions, related donors continue to far outstrip all other categories. Related donors rank, in proportion, from highest to lowest, in this dataset as follows: siblings 29%, parents 25%, child 11%, cousin 5%, aunt/uncle 2%, other relative 5% (with unrelated donors at: spouses, 13%, unrelated donors, 10%, and anonymous, less than 1%) (TGLN, 2011). Over time, the number of non-related donors has risen. From 1992 to 1999, a total of 10 living kidney donors in Ontario were unrelated, with annual double-digit numbers rising from 11 in 2000, to 40 in 2005, and 58 in 2010. Anonymous donors started with one in 2007, four in 2008, three in 2009, and seven in 2010.

When we look at the unrelated and anonymous categories in isolation, we see that in 2008, 2009 and 2010 about an additional 15 donors were added each year which may reflect the broadening of donor eligibility criteria addressed in chapter 8. The two specifically applicable policy changes are: the advent of non-directed donors in 2007; the launch of a national Living

Donor Paired Exchange program began in 2008. Any impact from the other two policy changes of gradually including more people as ‘related,’ and a provincial reimbursement of expenses program initiated in 2008 would be reflected in all categories of living donors.

This survey of what is publicly known lays emphasis on particular social categories. However, two questions remain. First, what about other social categories such as sex, race, class, age and citizenship? As we see in chapters 7 and 8, living donor exchanges are key sites of mediated social relations that could entail forms of subordination on the basis of these categories and others. International guidelines aimed at protecting living donors (reviewed in chapter 7) note that most living donors are women. This is true in Canada: females comprised 55 to 61 percent of all living donors between 1999 and 2008 (Canadian Institute for Health Information, 2009), and, “more males receive kidney transplants from their spouses”(Canadian Institute for Health Information, 2009). It is often noted that the gender imbalance may be due to the higher proportion of men in the ESRD, dialysis and kidney recipient populations. When I asked key informants about the living donor gender imbalance, a nephrologist said, “it’s the caring role,” insinuating that donation is natural for women (Tx 2). A donor team nurse at a different centre said, “I think the men are stepping up,” which was her anecdotal observation of a nascent trend (DT4). Other trends are also worth noting, for example, regarding age. In 2009, a trend of more living donors aged 55 and older was reported.³⁵ Other social variables are unknown either due to a lack of data collection or reporting, likely both. In relation to other countries, many reports note – often with pride – that Canada has a higher living donation rate per million population (reported in 2009 to be 14.4), than the international average of 7.4 (Canadian Institute for Health Information, 2009).

³⁵ In the only report produced by the specifically about donors

Second, how have Ontario's living donors fared? While plenty of reassurances of low-impact are available, there is no public reporting of postoperative health outcomes in the short, medium, and long term. Nor is it possible to ascertain whether medical eligibility criteria have changed over time. We see in chapters 5 and 6 that there is evidence in transplantation literature that not just social but also medical eligibility criteria have broadened to include donors categorized as "medically complex" (as indicated in Tables 3 and 6 above). Whether and to what extent such potential donors are accepted in Ontario cannot be ascertained from the available data.

Overall, Ontario's deceased and living donors are few relative to the size of the population. There has been more living donors than deceased donors since 1996 in Ontario. The number of deceased donors plateaued after 1978 and rose in 2006 only after a change to the pliable rules of medical guidelines diagnosing death. Living donors have been on a steady incline since 1982. Siblings and other kin are the overwhelming providers of kidneys but the trend is towards a more diverse pool of living donors. The types of social relations between live donors and recipients has broadened since 1992 to include more unrelated persons (who may still be non-genetically related family members), strangers donating at Ontario transplant centres anonymously or after public solicitation. And, since 1998, a small proportion of Ontarians with End-Stage Renal Disease have bought kidneys from providers internationally.

4.5 Two Systems

Beyond the fundamental rules of altruism and alienability and given the pools of potential donors, how are deceased donation and living donation organized in Ontario? The pools of potential donors identified in Ontario, as in other altruistic systems, are of persons dying from CNCs, and, living donors who know the potential recipient, mostly family. This section explains the similarities and

differences between how deceased donation and living donation, intimate giving and community-based giving, are organized.

In my previous research I uncovered that in 1983 American President Ronald Reagan began publicly soliciting parents of dying children, asking them to donate their child's liver to specific children dying of liver disease at the Children's Hospital in Pittsburgh. This was successful and fifty-one children became recipients. The establishment of organ procurement organizations around that time ended the practice of publicly soliciting on behalf of specific individuals for a direct donation. Since passage of the *National Organ Transplantation Act* in 1984 in the United States, the distribution of organs from deceased donors has adhered to a community model.

I have referred to the distinction between living and deceased, intimate and community as two types of altruism: *community altruism* and *intimate altruism*. The two types of altruism draw on the same ideological foundations but are organized differently. Table 10, below, illustrates the primacy of these four dimensions in the organization of altruistic exchange in Ontario.

Table 10 *The Organization of Kidney Exchange by Donor and Recipient Status*

Living	Deceased
Intimate	Community

Table 10 can be read for the vast majority of exchanges and the conventional organization of exchange, explained below, as two columns: living donors give directly to known recipients who are intimates, hence *intimate altruism*; and, deceased donors are strangers who give to strangers within the community, hence, *community altruism*. What we see in changes to living donation analyzed in chapter 8 is that the intimate – community distinction starts to blur. For example, *community altruism* is adopted in living donation by the introduction of non-directed donors,

meaning strangers, who voluntarily donate to another stranger. The introduction of *paired exchanges*, whereby immunologically incompatible dyads give to each other anonymously creates a qualified community in-between the two poles of intimate and community. Cases whereby deceased donor kin or anonymous living donors (either non-directed or *pair-exchanged* donors) later meet the organ recipient also put a wedge in-between the intimate and community categories.³⁶

In chapter 3, current changes led me to return to *Gift Acts* to establish a benchmark from which changes could be analyzed. Below, I follow the same pattern detailing the original organizational models for exchanging kidneys from deceased and living donors. Attention is paid to differences in how each system is governed. A final section compares how dimensions of governance and exchange influence the appropriateness of intermediaries asking for kidneys. What follows grounds the analysis in the ensuing chapters in general and provides an anchor for examining what has changed over the fourteen years under study.

4.5.1 Deceased Donor Community Altruism

Starting in the early 1980s in the United States and approximately a decade later in Canada, deceased donation follows a Community Altruism model managed by the state and founded on the principles of voluntary donation and fair distribution prioritizing need. A centralized

³⁶ See Sharp's (2006) research on deceased donor kin forming 'fictive kin' relationships with recipients after-the-fact of exchange. Among my own research participants, one deceased donor kidney recipient formed a friendship with the parents of her deceased donor who was ten years old when he died. His photo adorned her living room as her memorial of gratitude to him. As in Sharp's study, she approached the family at a TGLN organ donation promotional event. In coming to know one another the new 'kidney kin' breached the rules of privacy and confidentiality established in Ontario's *Gift Act* legislation and enforced by TGLN. In another case, a donor family included in my study conveyed how a deceased donor recipient befriended them as her imaginary 'kidney kin'. With their blessing, she honours their son – again a child when he died – in her organ donor advocacy work, carrying his photo, for example, while rowing for the organ donor team in Dragon Boat races.

“sociotechnical complex” characterizes these exchanges which are very time sensitive (Machado, 1998). Potential donors must be identified among ventilated dying patients in Intensive Care Units/Critical Care Units (ICU/CCU), death declared, consent secured, tests taken to ensure the health of the organs and laboratories engaged in matching blood and tissue type, lists consulted to identify potential recipients, transplant centres contacted with offers of organs to their patients, the surgery of nephrectomy (and other organ removals) organized, transportation minimizing “ischemic time” for each organ (by land or air) and transplant surgery organized at the receiving hospital. The managerial intermediary that governs this generative, co-ordinating and distributive work is an organ procurement organization (OPO).

Ontario is managed by an arms-length agency of the provincial government, the organ procurement organization, Trillium Gift of Life Network which was established by legislation passed in 2000. TGLN is the product of a lobby by organ transplanters for the province to do more to secure organs from ICU at hospitals across the province. Its mandate is to generate and allocate deceased donor organs for patients at provincial transplant centres. In rare jurisdictions, such as British Columbia, the OPO is also responsible for the budgets and management of transplant centres. Although under consideration, this is not the case in Ontario during the time period studied (2000 to 2014). Ontario had a more common model in place with separate reporting streams for transplant centres and OPOs. Centres adhere to direct legislation under the Gift of Life Act but otherwise fall under the regulations of hospital legislation, reporting to regional Local Health Integration Networks and then to the provincial Ministry of Health and Long-term Care. TGLN, Ontario’s OPO is a not-for-profit agency with a direct reporting relationship to the Ministry of Health and Long-term Care.

At the front lines in large hospitals are Organ Donor Co-ordinators, usually nurses who have access to the ICU/CCU but are employees of the OPO. They are responsible for educating and ensuring staff classify patients as potential donors and for notifying TGLN when such a patient is identified. Co-ordinators, as employees of the OPO, work *for* transplant candidates who cannot be present. They oversee the donation process: ensuring death is declared, approaching the potential donor's family for consent, co-ordinating testing and "donor management" to keep the organs alive until removed and transported. They support the "donor family" throughout the process and for a year afterwards.

Canada has an explicit consent regime whereby donors—or their substitute decision makers—grant consent. The Ontario model reflects Canadian consent regime standards. It is often argued that this practice should change to 'presumed' consent. Graciela Nowenstien (2013) provides an account of how, in France, organs were presumed to be given but medical providers came to seek the consent of families regardless. In 2010, Ontario launched an electronic registry system enabling Ontario Health Insurance Plan cardholders to register advanced consent to deceased donation on-line. Families nonetheless hold a veto power in deceased donation.

Central to consent is trust in allocation. Donors must trust that the OPO will adhere to the principle of equal access that organs are allocated based on fairness and equity. Weighted algorithms ensure that the patient in the greatest need who has waited the longest receives the next organs. In Ontario and throughout Canada, algorithm formulas are less public than in the United States where more of the rules and processes are posted on-line for public scrutiny. In both places, controversies have arisen over time regarding where boundaries should fall around organ sharing communities. As my interviews revealed, from one standpoint, OPOs are the servants of transplant centres. They do the challenging work of intervening in ICUs/CCUs *for* transplant physicians.

And, it was, after all, transplant physicians who created OPOs in order to connect to ICU/CCUs in hospitals other than their own. Another view is that OPOs serve transplant candidates, all of them, not centres. The clash between these viewpoints manifests in the issue of wait-lists: should there be one for each OPO or one per centre—a provincial or regional distribution or some combination thereof for paired organs like kidneys. On these grounds, a “battle for organs” has (largely quietly) ensued (Joralemon, 1995). Some observers have disputed the claim of equity in deceased donor organ allocation based on grounds as diverse as health care insurance, geography and, less often, blood-type (see for example, Davies, 2006; Daw, 2012; Koch, 2002).

4.5.2 Living Donor *Intimate Altruism*

As demonstrated above, kidney exchanges from living donors are conventionally – and still predominantly in Ontario – made between intimates, especially close kin. It is for this reason, as explained in the introduction, that I refer to the living donor system in Ontario as *Intimate Altruism*. Theoretically, however, as we saw in Table 5 in the previous chapter, almost anyone could be in the pool of potential living donors and many categories of persons are not relied upon or allowed in Ontario such as prisoners or minors. Yet in several instances Ontario public policy reports (and the report by demographer David Baxter mentioned in the introduction) cast an eye on living donation as an infinite potential donor pool. It was reported in the media, for example, that “experts on organ donation say the potential to increase the number of live organ transplants is boundless” (Vallis, 2001). This enthusiasm raises the importance of the rules that govern kidney exchanges from living donors.

What is significantly different between deceased donation and living donation is the governance structure. Where deceased donation is centralized with exchanges organized through

TGLN, the OPO, living donation is decentralized. Transplant centres are the sole sites at which living donor kidneys are offered, mediated and received. Other than adherence to the rigid rules of altruism – regarding consent and the prohibition against sales – decisions about potential donor acceptance are autonomous. We saw in Table 4 of the previous chapter that living donors must be adults who give explicit informed consent and exchange their organ strictly for the psychological benefit of doing a good deed.

With respect to the alienability of the kidney, all transplant practice is guided by medical research published in scholarly journals. However, the lack of an organ procurement organization intermediary in living donation makes the line between the international organizational and scholarly community and transplant centres more direct. During this period, of 2000-2014, Trillium Gift of Life Network played no role in directing the affairs of the six Living Donor programs at Ontario transplant centres. As we see in chapters 7 and 8, centres in Ontario are instead led – like their international counterparts – by their own protocols developed based on national and supranational medical/ethical statements and guidelines. These are detailed and analyzed in chapter 8.

Lastly, due the direct nature of living donation, there is no generalized exhortation to donate as we find TGLN leading in deceased donation *community altruism*. Asking for organs happens conventionally within inter-personal relations and it is intimacy that has served as the rationale for donation. We see, however, in chapter 8, how the pliable rules bend to broaden who is considered an intimate and weaken this standard as a basis for potential living donor approval or rejection. New types of living donors emerging through paired exchange ‘swaps’ and non-directed giving (which adopts *community altruism* for living donation) enable the promotion of living donation to the public at large.

4.5.3 Other Intermediaries: The Federal Government and Independent Living Donor Brokers

As we see in the chapters that follow, there are other important organizational actors with influence on how organ exchange occurs in Ontario. These are the Canadian Council for Donation and Transplantation (CCDT), which existed from 2002 to 2006, and Canadian Blood Services, which assumed the national role in donation and transplantation in 2008.

The CCDT's mandate to advise the Federal/Provincial/Territorial Advisory Committee on Health Services on ways to improve Canada's system of organ and tissue donation and transplantation means. In my analysis of CCDT's work, their mandate means that the organization's task is to identify ways to increase the number of organs available for potential recipients. As we see in the chapters that follow, the primary contribution of the organization was to host meetings of experts and release medical guidelines that changed the 'pliable' rules governing the legitimacy of removing (alienating) organs from persons. The major contribution of Canadian Blood Services is a Living Donor Paired Exchange program launched in 2009. This program registers incompatible dyads using an algorithm run four times a year to find matches for proposed kidney trades. This novel form of exchange is addressed in chapter 8.

Additionally, independent brokers of living kidney donation have emerged during the period of 2000-2014. For example, websites such as *matchingdonors.com* and *livingdonorsonline.org* established means for donor and recipient strangers to meet each other for the purpose of altruistic kidney exchange. As we see in chapter 8, all types of living donors use the message boards on the latter website to seek support, information and solidarity with other living donors. Some new autonomous intermediaries also broker commercial exchanges. The emergence of other actors means that the role once held only by government-sponsored

intermediaries (OPOs and transplant centres) is now occupied by a number of other entities vying to facilitate kidney exchanges. Transplant centres nevertheless make the final decisions on proceeding with donation and transplant surgeries.

4.5.4 *Appropriate Asking*

Before we turn in subsequent chapters to a deeper examination of each system, summarizing and comparing the differences between deceased donor *community altruism* and living donor *intimate altruism* reveals differences in when, how and from whom kidneys are asked for and the implications thereof. As detailed above, deceased donation *community altruism* is a centralized system involving three intermediaries between donor and recipient: the source hospital (specifically, the intensive care unit (ICU) or critical care unit (CCU)); the OPO; and the transplant centre. As we see in chapter 5, Ontario's OPO, TGLN, engages in extensive asking for organs as part of the work of converting potential donors to actual donors. Following Thorne (2000), I use the term *exhortation* to describe this form of asking the public at large to advanced consent to deceased donation. Asking for organs as gifts is considered acceptable because it is generalized – the organ will go to someone who is a stranger but a member of the community.³⁷ As Richard Titmuss (1970) envisioned, this form of exhorting organs is understood as asking for a contribution to the public good. It is in keeping with the spirit of both charitable giving and social welfare.

From the standpoint of my theoretical lens, another notable contributor to the ease of asking for deceased donation is the way in which organs are considered more alienable because donors

³⁷ Community is defined by the deceased donor allocation rules within any given jurisdiction. Generally, deceased donor organs are shared within the service area of a single organ procurement organization with membership based on residency and/or citizenship status.

are no longer persons. Further, the relationality between donor and recipients is highly mediated and closer to the idealized, pure gift because of rules of anonymity. It is in a sense less complicated by the challenges that can weigh on interpersonal relationships (as we see in chapter 8). But, as Godbout and Calle (1998) point out, giving to strangers is also understood as a step beyond the taken-for-granted forms of giving within family and among friends. We see in Chapter 7, several of these features elevate deceased donor *community altruism* to be the ‘system of choice’ in the eyes of anti-transplant abuse campaigners. However, as we see in the next two chapters, the confluence of a number of variables including the permissibility of more asking for gifts, the symbolic value of altruism, the higher degree of obscuring donor-recipient relationality, and, a public policy goal to increase the volume of organs contribute to the disjuncture identified as problematic in the introduction.

By contrast, live donor *intimate altruism* is organized following a decentralized governance structure. As we see in Chapters 7 and 8, there is only one formal intermediary between donor and recipient: the transplant centre. Each centre is autonomous, setting their own policies within jurisdictional rules, with practice influenced by professional guidelines. What this means is that compared to deceased donation, social relations of power are concentrated at the level of the transplant centre. Also, the intermediary of the transplant centre does not conventionally ask for organs for two reasons. First, because these gifts are less alienable; removing kidneys (or partial livers or lungs) is considered more of a sacrifice in carrying a risk of harm to the well-being of donors (including the risk of death). Second, because the relationality between donor and recipient is direct and known (in standard exchanges). Kidneys (and partial livers and lungs) are given directly; there is no principle of equality in access. Transplant candidates with a willing and qualified live donor are at an advantage over others without. For these reasons—of risk and

intimacy—exhortation is conventionally considered inappropriate. This said, we see in chapter 8 how the expansion of the pool of living donors and novel models of exchange ‘bend’ altruism in ways that make exhortation more permissible. Canadian Blood Services’ Living Donor Paired Exchange program is a case in point. This program establishes *community altruism* in living donation, and, in 2014 this agency (which I have noted is less direct intermediary of kidney exchange) began advertising for non-directed donors in a similar fashion as we see in deceased donation.

4.6 Conclusion

This chapter has laid the groundwork for the chapters that follow by presenting a profile of Ontario’s kidney transplant recipients and donors. To review, potential recipients are patients with End-Stage Renal Disease who must replace their renal capacity through dialysis or a kidney transplant in order to survive. Immunology and its suppression is central to the success of organ transplantation and the current technology orders the value of any potential donor’s kidney for a given recipient. Only some kidney exchanges work for some time, and some work better than others. Ontario’s kidney providers are overwhelmingly related but increasingly diversified.

While intentionally neglecting the role of organizational intermediaries in this chapter, I established the first part of my central argument that there is a tension between donors, intermediaries and recipients – the three primary parties to transplantation that results from valuing kidneys apart from persons. Most importantly, I have argued that kidney transplantation is a complex therapeutic modality. Five different developments are necessary to enable transplantation anywhere: 1) investment; 2) medical authority and jurisdiction; 3) demand and success; 4) pools of potential donors and access to them; and, 5) techniques to convert potential donors to actual

donors. It was shown how different rules create different pools and conversions. A broad approach is taken in order to appreciate how transplantation is deeply embedded in a society in multifaceted ways.

The purpose of explicating the factors necessary and enabling for transplantation is to lay the groundwork for examining when, where and how limits are set and boundaries pushed in the effort to increase organ supply. Through the donor profile, boundary pushing is already evident but not yet analyzed. The following chapters delve into the pursuit of kidneys in deceased, led by the Trillium Gift of Life Network, and living donation negotiated by transplant centres. What we see is that the rigid rules regarding consent take centre stage while the pliable rules are not subject to public engagement.

Chapter 5 Altruism and the Discourse of Donation

This chapter is devoted to illustrating and analyzing a virtually seamless discourse over the period of 2000-2014 that calls people into holding a recipient-centric orientation. This is done targeting the public in the very fashion that we saw in chapter 3 articulated in 1972 for hospital staff: by “constantly remind[ing] physicians of the needs of other patients,” and exhorting members of the public to give (advanced) consent to deceased organ donation as “a responsibility to the community” (G.C. Oosthuizen, 1972). I call this the *discourse of donation* and I argue that it is the dominant framework of understanding that deflects attention from the significance of alienability (in other words, the legitimacy and limits of removing kidneys from their owners).³⁸

Historical evidence from 1985 to 2014 is drawn on to show how this discourse came into use in Ontario, its characteristics (asserting a moral cause and relying on specific evidence), and the shifts in emphasis over time. The sources of the discourse of donation and the breadth of adherence to this understanding of organ exchange are also demonstrated. Data include public policy reports and media campaigns. In chapter 6, I show what the discourse of donation deflects attention from by analyzing data that reveal tension between recipients and deceased donors over alienability.

Through my conceptual lens, I see this discourse of donation as central to the ideational work of converting potential donors into actual donors by securing consent to organ removal. I analyze how the discourse frames the meaning and knowledge of organ exchange. The problem is that

³⁸ This term is one I created and used in my previous study to describe the meaning ascribed to deceased donor organ exchange during the years 1967 to 1999. I use it here because I found that the core messages had not changed.

there is an organ shortage caused by an imbalance between demand and supply. By virtue of calling the imbalance a shortage, demand is not the problem; it is supply that is the problem. The two standard solutions to the organ shortage problem within the *discourse of donation* are therefore supply strategies: 1) (advance) consent to deceased donation; and 2) hospital efficacy.

This chapter is organized chronologically. I start my analysis of the ‘discourse of donation’ by showing an important shift that occurred between two public reports: one in 1985, the other in 2000. The former addressed the size of the potential donor pool; the latter, Premier Harris’ Report (hereafter Harris’ Report) of 2000, did not, replacing evidence with a caveat regarding the size of the pool of potential donors instead. The caveat is a disclaimer acknowledging that the size of the pool of potential donors may undermine the efficaciousness of consent or hospital intervention. I interpret this shift and other ways the Harris’ Report frames the issues as a turn setting a precedent followed throughout the remainder of the period under study.³⁹

As we see, from 2000-2014, the altruistic act of donating organs became a dominant rallying cry for a moral cause while the complexity of supply – the question of whether a sufficient pool of potential donors exists in the first place – is marginalized in public policy reports and receives no public attention. The impression given is that increases in rates of consent to donation and strengthening hospital efficacy are all that are needed to solve the organ shortage problem. When Premier Harris’ goal to double the donor rate by 2005 is not reached, policymakers hold another inquiry in 2007 and invest further, this time with greater emphasis on advanced consent to

³⁹ Note that I developed the concept of a ‘discourse of donation’ in my previous study completed in 2001. After conducting the research for this study I decided to employ the same term because the discourse in Ontario from 2000-2014 was consistent with the earlier period. The shift, therefore, of the Harris Report is predominantly in regards to the change in evidence required to justify intervention. The frame articulated in the discourse of donation of recipient-centrism and organ shortage, as the exclusive problem to be solved, was already firmly in place.

deceased donation. This pattern of looking to the same two solutions is repeated in a third public policy report in 2009.

What is obscured by the focus of public policy reports and media campaigns on organ donation is the fact that around 2005-2007 experts abandoned sole reliance on the two standard solutions (increasing consent to donation rates and increasing hospital efficacy). Instead they looked at and changed deceased and living donor eligibility criteria to expand the pool of potential donors. I conclude this chapter by showing how it is that the seamless discourse of donation, with its blindness to the donor pool and issues of alienability, leads to blaming altruism. Further, the logic of the discourse of donation is shared between the argument for more intense altruism and the argument in favour of turning to monetary incentives as an alternative strategy.

It is important to note that what follows does not deny the shortfall of organs relative to demand, disapprove of recipient-centrism, or propose that the two standard solutions will not make a difference to the deceased donor rate (I demonstrate, in fact, high consent and hospital efficacy rates will improve the rate). What I critique is the way in which rhetoric replaces evidence, how consent and hospital efficacy are presented and understood as the only variables that matter, and the repercussions that follow from the denial of limits inherent in the over-emphasis on these two variables. At stake is the effect of this social construction pointing to government, the population, and, at times, moreso particular sub-populations, as at fault for the organ shortage, with significant ramifications for public policy. I find competing explanations provided by experts identified in this chapter and the next one that take the size of the potential donor pool into account more persuasive than the claim that the two standard solutions of consent and hospital efficacy will solve the organ shortage.

5.1 The Shift from Measuring the Pool of Potential Donors to Caveats

In this section I provide a historical comparison of two public policy reports, fifteen years apart (1985 and 2000) for two purposes. First, I substantiate my theoretical account of how kidney exchange for transplantation works (articulated in chapter 3), by showing how transplant physicians seek to identify a source of organs and then find ways to convert potential donors into actual donors. Herein, we see the initiation of what I argue is a new role for hospitals, to be sites of production tasked with creating organs as ‘medicine’ in addition to sites of healing. Second, the contents of the 1985 report compared to the year 2000 report illustrates a significant shift in approach. As I argued in the introduction, the framework for understanding deceased donor organ exchange employed by the 2000 Harris report set a precedent that dominated the next fourteen years. This framework is one of altruism (implicitly contrasted with markets) and one of *structured forgetting* in presuming – rather than needing to establish – the existence of a pool of potential donors and its size.

5.1.1 Organ Donation in the Eighties

In the early 1980s, as kidney transplants proved increasingly successful, the volume of kidney transplants, as well as the range of organ transplants offered by transplant centres, began to expand. To address the need for more organs to feed the growth in transplant programs, in 1985 a public policy report was produced in Ontario titled *Organ Donation in the Eighties: The Minister’s Task Force on Kidney Donation* (hereafter the “1985 report”), which included six categories of recommendations (Ontario, 1985). This report provides a touchstone for comparing and contrasting three similar reports produced from 2000–2009 as discussed below. In particular, the 1985 report reflects a different era in the transplant world, when less was taken for granted and more evidence was presented to make the case for greater investment in organ acquisition efforts.

Table 11 *Special Reports on Organ Exchange, Ontario, 1985-2009*

Year	Author	Title
1985	Ontario	Organ Donation in the Eighties: The Minister's Task Force on Kidney Donation
2000	Ontario	A Plan for Change and Action: Report of Premier Harris' Advisory Board on Organ and Tissue Donation
2007	Ontario	Report of The Citizens' Panel on Increasing Organ Donations: Seeking views and opinions on increasing organ donation in Ontario
2009	Ontario	Report of the Organ and Tissue Wait Times Expert Panel

The 1985 report opens by painting a picture of the situation in Ontario in the mid-1980s. At the time, Ontario was considered to have a highly efficient organ retrieval system and a higher rate of transplantation than both Canadian and American averages. The number of kidneys donated in Ontario in 1984 was 281, with 265 having been transplanted—a figure that does not distinguish between live or deceased donors (Ontario, 1985: 6).⁴⁰ The transplantation rate per million population is reported to be 29.7, which put Ontario ahead of the Canadian average of 26.1 and the American rate of 20.6.⁴¹

The problem, as identified in the report, was that the number of dialysis patients in Canada doubled from 1976 to 1981 and has steadily continued to grow. About 40 percent of the rising dialysis patient population are Ontarians. Transplantation was described as the recommended form of therapy, but the alarm was raised as to the “increasingly inadequate supply of donated kidneys,”

⁴⁰ As reported in chapter 4, the TGLN TOTAL database reports the number of kidney donors for that year, 1985, as 165 (139 deceased and 26 live).

⁴¹ Note that 29.7 is a transplant rate, not a donor rate and may include living donors (although there were few in the 1980s). The veracity of this figure and (in the next paragraph) the donor rate of 26 per million population should be read with caution.

which was seen to be an “escalating crisis” (Ontario, 1985: 11). To meet the need, a goal of tripling the number of donors from 26 per million population to 75 per million population—counting deceased and live donors—was set. Subcommittee reports addressed three objectives: (a) document that there was in fact a potential to increase the supply; (b) identify existing barriers to organ donation; (c) and recommend changes to overcome the barriers. The overall stated goal was “to effect an increase in the kidney donation and transplantation rates” (Ontario, 1985: 11). Recommendations for improving the organ procurement system changed only minimally over the next twenty-nine years, and, as discussed below, most were not realized until after 2002.

The 1985 report’s inclusion of evidence demonstrating the potential to increase supply was logical but unique; no subsequent report repeated it. Three methods were used to calculate whether acquiring more kidneys from deceased donors was possible. Each method measured the conversion of potential to actual donors by relying on death statistics, detailed death audits, and fatality rates from car accidents—the most common donor source. A large gap between potential and actual donors in each method served as evidence of room to grow the number of organs available from deceased donors for transplantation.

How transplant physicians might access potential donors was also openly considered in the 1985 report. For example, in addressing the value of regional trauma centres to transplant transportation logistics, it recognized that,

By providing this treatment facility [trauma centres] to as many as possible, not only was it noted that there will continue to be a decline in trauma-related mortality, but inevitable treatment failures will be more readily available for organ donation (Ontario, 1985: 21).

While intended to note the benefit of geographically concentrated potential donors to organ acquisition efforts, this statement reveals an awareness that the size of the deceased donor pool is

contingent upon mortality patterns that are themselves incumbent upon incidence and treatment outcomes. Such variables are not, however, integrated into the optimistic projections for increasing the donor rate.

The majority of the report was devoted to the second and third task force objectives: identifying and providing solutions to barriers to organ donation. Six categories of barriers were identified: (a) hospital, (b) medical, (c) public, (d) transportation, (e) structure of the provincial organ retrieval program, and (f) living donors. In the report's recommendations for overcoming those barriers, emphasis was placed on shifting from *ad hoc*, occasional procurements to standard practices. Authors called for numerous measures to this end: expansion of the Multiple Organ Retrieval and Exchange Program (a precursor to TGLN), hospital committees, organ donor coordinators, systems, training, rules, cost coverage, transportation logistics, guidelines, and criteria for identifying potential donors. Living donation was promoted by recommending education of kidney transplant candidate family members, evaluation by an independent physician, reimbursement of direct costs, and a study of broadening eligibility criteria to include "emotionally related donors" (Ontario, 1985: 31). With respect to public barriers, it was stated that "an imaginative, ongoing public information program is required to focus on the urgent need for donor organs, the successes of transplantation and the positive effects of transplantation, both medical and economic" (Ontario, 1985: 31).

The 1985 report's impact is difficult to ascertain. In 1986, the federal government produced and disseminated two guidelines—one for organ and tissue donation, the other for vital organ transplant centres (Canada, 1986a, 1986c). In Ontario, most efforts to acquire more organs from deceased donors remained local with different degrees of success in the major cities of Toronto, Kingston, London, and Ottawa. London's Multi-Organ Transplant Centre was particularly

successful, for example, in securing the support of community corporations to pay for advertising and fund activities of an awareness committee that oversaw organ donation publicity (London Health Sciences Centre, 2004). Initiatives to fund hospital-based organ donation coordinators were funded by private donations to individual hospitals; for example, in Waterloo, by an insurance company, and at St. Michael's Hospital in Toronto, by a major financial donor (OPO 1). Over time, more organ transplant centres began to collaborate and The Multiple Organ Retrieval and Exchange Program which evolved in 1998 to Organ Donation Ontario, with additional responsibilities, such as promoting organ and tissue donation in the province, maintaining transplant waiting list databases, and overseeing the implementation of standards and guidelines.

The 1990s ended with two developments. First was the House of Commons Standing Committee on Health inquiry described in the introduction. Its goal was to promote organ donation while examining legislative solutions. Then federal Minister of Health Alan Rock announced that the study would, "look at the donation crisis in Canada" and the federal role in alleviating the organ shortage (Canada, 1999c: 3). The report, with the sub-title, "A Canadian Approach," emphasized altruism to set the country apart from the debates over introducing monetary incentives to donate organs that had emerged in the United States. Twenty-million dollars was also devoted over five years to a number of initiatives, "for the development and execution of a program to increase safe organ and tissue donation" (Canada, 2001). Part of this money was earmarked to fund a new organization, the Canadian Council for Donation and Transplantation (CCDT),

mandated to develop a “national strategy to enhance organ and tissue donation and transplantation” (Canada, 2001).⁴² The evidence included in the press release was as follows,

Current data shows Canada has a donor rate of 14 per million, compared to 21 in the US and 31.5 in Spain. Almost 4,000 Canadians are waiting for an organ transplant, and about 150 die annually because an organ is not available (Canada, 2001).

As in 1985, the central focus is on deceased donation and the measure of success is calculated as a donor rate per million population (DPMP). This chronology brings us to the events that opened the thesis.

5.1.2 The Millennium Challenge

It was on the upswing of federal involvement in organ transplantation that Ontario Conservative Premier Mike Harris issued a bold *millennium challenge* to double the rate of organ and tissue donation from deceased donors in Ontario in five years. A Premier’s Advisory Board on Organ and Tissue Donation was struck to develop recommendations to meet the Premier’s goal. The four-month inquiry by the high profile advisory board included celebrity television sports commentator and organ donor advocate Don Cherry. The Board consulted transplant experts in Ontario and in select provinces, as well as select American organ procurement organizations.

The report, released in 2000, titled *A Plan for Change and Action: Report of Premier Harris’ Advisory Board on Organ and Tissue Donation* (hereafter Harris’ report), opened with a litany of problems: (1) a terrible shortage of organs and tissue; (2) 1,731 people on waiting lists; (3) an estimated 100 Ontarians died waiting in 1999; and (4) predictions that waiting lists will

⁴² Money was also committed to the Canadian Standards Association to establish safety standards for institutional testing and handling of organs and tissues.

continue to grow, patients will wait longer, and “more people will die waiting if nothing is done” to improve donation (Ontario, 2000: 17). No historical context was provided in the report.⁴³ The report put forward Spain, “the country that has led the attack on low donation rates, at 35.6 dpmp,” and two American OPO jurisdictions as evidence to show that, by comparison,

Canada and Ontario do not fare well. We are convinced that our poor performance does not mean that Canadians or members of our medical community are not supportive of organ and tissue donation or lack compassion and generosity. Indeed, we believe that the opposite is true, as shown by a survey conducted as part of our work. What has been lacking in our Province and our country, and what has worked in Spain, Texas, Delaware Valley and a small number of other jurisdictions is good management, organization, education and resources (Ontario, 2000: 17).

The argument advanced in the report was that if these jurisdictions could reach high donor rates, so could Ontario. As in the 1985 report, it was the procurement system—or lack thereof—that served as the primary explanation, and the solution, for the low rate of donation.

Sixteen recommendations were made in Harris’ report, which was released in June 2000 to a great deal of media attention. The report largely repeated the barriers and recommendations identified in the 1985 report. There was an almost exclusive focus on improving standard hospital efficacy. Lost donation opportunities were blamed on “failure to properly perform any of the steps,” such as death diagnosis, declaration of death, approaching the family for consent and medical staff performing “donor maintenance” (Ontario, 2000: 1). Even refusal to consent was attributed not to families or individuals but to consent requests asked in an inappropriate location, time, or manner by an untrained requester. This complements the view that donation “occurs in a

⁴³ The direction and extent of shift in donors per million measure is curious. Assuming these numbers – as cited in the 1985 and 2000 reports are correct – over the fifteen years, the province moved downward from a high rate of transplantation at 29.7 donors per million people to a rate of 14.1 donors per million people (Ontario, 1985) (Ontario, 2000).

setting of personal tragedy for the family of the potential donor, who must deal with the loss of a loved one while considering whether to consent to organ and tissue donation” (Ontario, 2000: 21). The solution of education and awareness to overcome “attitudinal and knowledge barriers” was therefore focused on hospital staff, less on the public (Ontario, 2000: 1). Public education, the report claimed, would best be performed by stakeholder organizations with education materials and evaluation research on effectiveness disseminated by a central body.

Significant changes recommended in the Harris report, with great optimism, were mechanisms to standardize organ acquisition, such as: (1) establishing an organ procurement organization in Ontario (Organ Donation Ontario was considered too underfunded and lacking clout to be considered an organ procurement organization); (2) hiring in-hospital organ donation coordinators; and (3) imposing new requirements on hospitals to ensure participation in the organ donation process. As a result, Trillium Gift of Life Network (TGLN) was created through new legislation that granted this arms-length government agency significant powers to exercise over hospitals in order to acquire organs. Designated hospitals would now practice *required request* whereby staff must inform the family of the option to donate organs and tissues, and *routine referral* whereby staff must contact TGLN upon identifying a potential donor.

In a section called, “Some Facts about Donation,” brain death is defined and its primary causes are described as “massive head trauma (frequently caused by a motor vehicle accident or similar tragic event) or an intracranial hemorrhage” (Ontario, 2000: 20).⁴⁴ Unlike the 1985 report,

⁴⁴ It is also recognized that in some jurisdictions, there are efforts to procure organs from ‘non-heart beating donors’, after the heart stops but who are not brain dead. Such donors – later called DCD, for Donation after Cardiocirculatory Death – are currently only able to donate tissue in Ontario. The Advisory Board “strongly encourages investigation of all efforts that can ethically increase the organs available for transplant” (Ontario, 2000: 21).

the issues of organ transportation and re-transplantation were ignored, and the success of trauma treatment was not recognized as relevant.

Also, unlike the research on the size of the potential donor pool included in the 1985 report, Harris' report deals with this issue by adding a disclaimer. The commitment to double the organ donor rate by 2005 was considered reasonable.⁴⁵ "We're not talking huge numbers here," said one Advisory Board member to the *Toronto Star* newspaper (Boyle, 2000). But the Advisory Board nonetheless thought to include a caveat regarding the Premier's ambition:

The Advisory Board strongly endorses the goal of doubling the rate of organ and tissue donation in our Province. There is one caveat to Ontario's ability to achieve its goal. Simply put, achieving this goal could be more difficult in Ontario because *Ontario may have fewer potential donors than the most successful jurisdictions. We do not have accurate information on the number of potential donors in Ontario.* We know, however, that certain types of injuries involving major head trauma are less common in Ontario than in other jurisdictions, probably because seat belt and motorcycle helmet laws are treated more seriously and we have fewer deaths from gun shots.

In addition, we have a more diverse population than most jurisdictions and with diverse populations come diverse attitudes and beliefs which can affect the willingness to consent to donation. Trillium Gift of Life Network *must get an accurate assessment of the number of potential donors* and the effect of ethnic attitudes on donation. *If there are fewer potential donors, we must know why and adjust our plan* to deal with the situation. In the meantime we must strive to achieve the Premier's Goal, even if it means overcoming challenges not present in other jurisdictions (Ontario, 2000: 22, emphasis added).

This note of caution, buried deep into the report, clearly identifies two problems, only the latter of which remains recognized over the next 14 years: the size of the pool of potential donors and, "the effect of ethnic attitudes on donation" (Ontario, 2000: 22). Setting aside the "ethnic attitudes"

⁴⁵ Using TGLN TOTAL database numbers, as reported in chapter 1, from 132 to 264

issue for the moment, we see a lack of information on the number of potential donors also addressed in passing in the eleven-page executive summary. Using the words “serious” and “essential,” the Advisory Board stated that accurately determining the number of potential donors was necessary to measure success and judge performance (Ontario, 2000: 3). But the need for improved data was absent from the list of sixteen recommendations.

Comparing the 1985 report to the 2000 report, a key shift in public policy was as follows. Both reports use a deceased donor rate measured per million population and compared by jurisdiction as evidence to show that improving the deceased donor rate is possible. However, the 1985 report calculated the size of the pool of potential donors whereas the Harris report does not. The variable of the size of the pool is addressed by including the caveat cited above which acknowledges that the size of the pool may undermine the ability of any of the recommendations to increase the deceased donor rate. Overall, no evidence is provided to show how any of the recommendations (falling into the two categories of consent and hospital efficacy) will make a difference in raising the annual rate of deceased donors. Notably, there is also no evidence presented to support the claim that Ontario’s “more diverse population” affects the willingness to consent to donation.

Recalling the story presented in the introduction, Ontario’s organ supply strategy from the time of the the Harris report onward ignores the concurrent report by David Baxter warning that the current pool of potential donors is insufficient. Ontario forges ahead based on a presumption that the organs are “out there,” and just need to be identified, that consent must be secured, and donors must be converted from potential to actual donors through standardizing and systematizing hospital procedures. This reflects Kieran Healy’s interpretation of the altruism versus market debate in American jurisdictions: “The assumption is that once the overall exchange system is

fixed, certain consequences for the volume and composition of the supply will tend to follow” (Healy, 2006a: 1017). And, the idea that intensified altruism will be sufficient also reflects the spirit captured in Lesley Sharp’s (2014: 25) idea of a transplant imaginary, that “if only” we get the right system in place, the organs will come.

Central to the discourse of donation is the evidence; the international comparison of donors using the ‘per million population’ measure becomes further entrenched at this time. The sense in presenting international comparisons is that, ‘if they can do it, we can do it,’ in keeping with a trope of national competitiveness and damaged pride that Ontario (or Canada) is not excelling. The ‘we can do it’ spirit is heightened by the simplistic presentation that the problem can be fixed; all that is needed is more altruism which is claimed, always, to already be part of the moral fabric of the nation. The Harris plan proceeds, from 2000 to 2005, on the basis of this evidentiary formulation, resting on the claim that changing the donor rate is amenable to intervention without changing the fundamental rules regarding terms of consent (of altruism) or the size of the pool of potential donors (rules of alienability). As a reminder, in chapter 6, I explicitly address the issue of the size of the pool of potential donors and how organ donation is measured.

Later when we look at the 2007 policy report we see another shift. Gone from the 2000 report is recognition of tragedy – of the death of the donor (and mention of causes) and related difficulties for the families. In its place is a rights-based discourse promoting the right to donate of the individual – that the family ought not veto their advanced consent – and of the family; both parties desire donation. Thus, the family no longer struggles with the legitimacy of removal (alienability hindered by acceptance of brain death and attachment), now the family is harmed if they are “denied the opportunity” to donate. The role of the family vis-à-vis donor protection and

benefit from organ donation is a theme that calls for further research beyond the scope possible here.

As stated above, what is continuous through this period, 2000-2014, is the construction of what I call a ‘discourse of donation’. Through my analytical lens, this discourse is recipient-centric. It interpolates people to adopt the viewpoint of potential recipients and establishes relinquishing body parts as morally praiseworthy and desirable. The problem and solutions always point to the source of treatment: the donors, on the supply side of the equation. And, alienability, whether giving is possible or not, remains absent from this discourse. In *community altruism* the emphasis is on consent as the choice to give, constructed as an obligation of membership in the provincial/national community. The discourse of donation thereby allows for blame and action whereas seeing the relationality of potential deceased donors to potential recipients removes blame and reduces the scope of action. Limits to action are visible when it is recognized that there are not enough deceased donor kidneys because not enough people are dying of catastrophic neurological conditions.

Another continuity initiated in 2000 is the racialization of the problem of insufficient organs. As we saw above, “diversity” and “the effect of ethnic attitudes on donation” are blamed for low rates of donation, in addition to fewer catastrophic neurological condition deaths (Ontario, 2000: 22). Both the way in which the ‘discourse of donation’ works in *community altruism* to present consent to organ donation as an aspect of belonging, and therefore a performance of citizenship within the community, and, the identification of some people – the religious and racialized – as problematic deserve far more analyses than is possible in this study. The line of argument followed in this thesis challenges the heightened significance of consent altogether. “Diversity” as a problem is nonetheless noted throughout and two observations are due on this

point for future elaboration. First, while a body of literature emerges during this period racializing nonconsent by attributing refusals to donate organs to religion and culture, there is no evidence presented in any Ontario publication to support the claim that “diversity”/“ethnicity” is a “barrier” to consent. The fact that race/religion is taken for granted as a problem is, in fact, notable and in keeping with the absence of evidence on other transplant issues, and broader social constructions of race in relation to community and in Ontario and Canada specifically (see, among others, Anderson, 1991 [1983]; Isin & Nielsen, 2008; Razack, 2013). Second, while TGLN devotes particular attention to sub-populations of Ontarians over this period, the organization follows a more restrained path than in the United Kingdom. Ciara Kierans and Jessie Cooper (2011, 2013) document the explicit social construction of the ‘ethnic donor’ in that country with large-scale publicity campaigns specifically blaming and targeting ethnic minorities to register as organ donors (with a Black campaign and South Asian campaign). In the UK nonconsent by ethnic minorities is explicitly tied to longer wait-times for ethnic potential recipients. By contrast, at no time is any sub-population of potential recipients identified in Ontario as waiting longer. The emphasis in Ontario is also placed on religion and the outreach strategies chosen by TGLN are more subdued than mass advertising campaigns, for example, seeking public endorsement for organ donation by religious leaders and producing information brochures in multiple languages.

Returning to the focus on the size of the pool of potential donors, we see in what follows how the caveat about the pool made in 2000 – which could critically limit any and all efforts to increase the deceased organ donor rate – was kept in the shadow of public attention. And in chapter 6, we see quantitative evidence that shows consent to be not more but only as important as other variables.

5.2 The Establishment of Trillium Gift of Life Network

The Trillium Gift of Life Network became operational in 2002, which caused a delayed start reaching Premier Harris's target to double the donor rate by 2005. From the outset, the organization was divided into departments, one of which conducted consent work (understood as education and awareness) predominantly targeting the public (but also the moment of consent in hospitals) and hospital-based work aimed at establishing donation programs within Intensive Care Units/Critical Care Units (ICU/CCUs) of provincial hospitals. In this chapter I analyze only the former, while an analysis of the latter appears in the following chapter.

As brought into the limelight by Premier Harris, consent work involves the social construction of the meaning of organ exchange, which I argue occurs through the discourse of donation. The main ideas of this discourse are articulated most clearly in public relations and communication campaigns. I found in my interviews that recipient-centrism is embedded in every part of Trillium Gift of Life Network. As identified earlier, the mandate of TGLN is to work for potential recipients and transplant centres to acquire organs on their behalf. The sense of moral cause in the discourse also provides staff with a sense of a much broader purpose to their work. TGLN uses this orientation towards helping patients with organ failure in all of its work. For example, in working with hospitals, their approach relies on persuasion to join the cause of organ donation more than the heavy hand of exerting authority (encoded in the new *Gift Act* legislation that established TGLN).

In all that they do, and especially in reaching out to religious and "ethnic" groups and targeting youth, TGLN aims to instill what they come to call a 'culture of donation' which reflects what I have been calling, from a critical perspective, the discourse of donation. As we see, this 'culture' is sought in two locations: the public-at-large and in ICU/CCUs across the province. As

we see in section 5.4.1 below, the culture of donation is measured by actions that signal consent to donation, and promote organ donation as a moral cause. This culture is recipient-centric in orientation and, when directed at the public, its emphasis is on belonging and community. As such, the ‘culture,’ establishes organ donation as an obligation of membership in the community and part of what it means to be a good citizen.

Below I detail some of the many ways TGLN seeks to instill the ‘culture of donation’ within the public along with the contours of the discourse of donation. This allows me to illustrate how independent parties join TGLN in advancing the cause of organ donation. Prior to continuing with this line of argument, I interrupt it to document the shift taken by experts in 2005-2007 in the next section.

5.3 2005-2007: Changing the Pools by Changing the Rules

This section demonstrates my claim that one of the most remarkable observations about the way in which the discourse of donation works lies in noticing what is missing: recognition that, starting in 2005, experts – including TGLN – changed the medical boundary lines that established the original pool of deceased donors. Based on a careful reading of my data, I highlight the shift away from the overwhelming focus on the two standard solutions of consent and hospital efficacy towards other strategies – regarding the pool of donors – that are absent from the discourse of donation. Here we see experts stating that the pool of potential donors – based on brain death diagnosis – is too delimited to meet organ supply goals. Since the contribution of the public to healing the ill through transplantation is only to consent to organ donation, the public is not invited to engage in considerations of where lines demarking alienability – either death or degrees of risk of harm to living donors – should be drawn.

Since the early 1970s, brain death has served as the diagnosis that legitimized categorizing patients as potential donors and for declaring death in numerous countries including Canada (for a full account of this process in Canada, see McKay, 2001). However, some countries, reportedly in Europe, also use a cardiac-based standard. In 1995, a team of physicians established the Maastricht classification to establish five categories of non-heart beating donors. This group of donors are patients whose hearts have stopped and who have a prognosis of brain death. The key distinction of this classification scheme is between *controlled* and *uncontrolled* Donation after Cardiocirculatory Death (DCD), referring to different points-in-time in the process of organic decline. Timing is crucial to deceased donation because of the need to establish the end of personhood (in other words, death) while organs remain viable. The key event (in what was first called non-heart beating cadavers and is now called Donation after Cardiocirculatory Death (DCD)) is cardiac arrest, which is anticipated in “controlled DCD” and unanticipated in “uncontrolled DCD”.

Table 2
Maastricht Classification of Controlled and Uncontrolled Donation after Cardiocirculatory Death (DCD)

Number	Category of Non-Heart beating Donor	Controlled/Uncontrolled
1	Brought in dead	Uncontrolled
2	Unsuccessful resuscitation	Uncontrolled
3	Awaiting cardiac arrest	Controlled
4	Cardiac arrest after brain-stem death	Controlled
5	Cardiac arrest in a hospital inpatient	Uncontrolled*

Source: (Kootstra, Daemen, & Oomen, 1995)

*Category added in 2000.

In February 2005, experts began a process of deliberations, facilitated by the CCDT, described as “national, multi-disciplinary, year-long” regarding “whether and how to proceed with organ donation after cardiocirculatory death (DCD) in Canada” (Shemie et al., 2006: S1). TGLN’s

annual report of 2006-2007 describes how broadening deceased donor eligibility criteria was an organizational goal: “TGLN identified bringing DCD as a donation option for patients and families to Ontario as one of its main goals in both its 2005/06 Annual Report and its 2006/07 Business Plan” (TGLN, 2007a: 10). Changing the size of the pool was a key supply strategy for increasing the volume of deceased donor organs. These efforts led to the publication, in October 2006, of “National Recommendations for DCD in Canada” which recommended starting with “controlled DCD” donors (Shemie et al., 2006).

In June 2006 (prior to the release of the guidelines) Ontario had its first case of organ donation from a donor using DCD criteria for death, heralded at the time as marking a “new era” for organ donation (TGLN, 2007c). The father of this donor Emile Theirien became an organ donor advocate who has worked with TGLN to promote DCD. Consistent with the discourse of donation, publicity has been positive, highlighting the desire of the family to honour the wishes of the deceased to give to others by consenting to organ donation and noting that the new criteria provide the opportunity to give that adherence to the brain death standard denies.

Thus, the release of the guidelines changed the definition of death by recognizing death based on cardiac cessation criteria instead of neurological cessation criteria. What this did is expand the pool of potential organ donors. Since 2006, donors whose death was determined by lack of heart function are classified as DCD donors and brain death donors became classified as NDD donors for neurological determination of death. DCD was accepted in Canadian jurisdictions over the next few years. However, by the end of the period of study, 2014, DCD was not yet accepted in Manitoba, New Brunswick, Saskatchewan and at Calgary Foothills Hospital in Alberta (even though DCD is accepted in the other major city in the province, Edmonton; Alberta is

divided into two OPOs). Disagreement that DCD is death is one reason for non-acceptance which I address in chapter 6 (section 6.2).

As we saw in chapter 4, DCD is the only policy change in Ontario that is recognized to have made an impact on the goal of increasing organ volume (Hernandez-Alejandro et al., 2011: 599). By 2011–2012, 18.5% of all deceased organ donors in Ontario came from this category (TGLN, 2012: 7). As we see in the next chapter, DCD has not been accepted everywhere in the country and the dissent by a few physicians expressed in articles published in medical journals became public in 2010 and 2014.

Through separate deliberations, also facilitated by the CCDT, experts also turned their attention to living donors. The first key assumption from a CCDT (2006: 2) *Living Donor Forum* held February 9-12, 2006 is as follows: “transplant waiting lists in Canada are growing and deceased donor organ transplant *cannot meet the demand*”.⁴⁶ The second key assumption is that, “live donation has developed as an important alternative to deceased donor organ procurement” (CCDT, 2006: 2). In my reading, these statements further demonstrate that transplant physicians and intermediaries determined the boundaries around the pool of potential deceased donors too restricted. These statements signal that the recipient-gaze of Canadian organizational intermediaries (mandated to increase the organ supply) now turn toward live donors as the more promising source of organs. This vindicates David Baxter’s finding, noted in the introduction, insofar as he demonstrated that the current deceased donor pool is too small. And this turn, six years later, follows Baxter’s recommendation to look to live donors instead.

⁴⁶ This document constitutes the *CCDT guidelines* for living donation analyzed in chapter 7.

Lastly, buried beneath a dominant focus on consent to organ donation, a report two years later, the Citizen's Panel notes that, "The message in the numbers is clear. Donations from the brain dead cannot meet the need" (Ontario, 2007: 13). As we see in the analysis of this report below, this argument and its implications are found only in the depths of the report and not included in any of the Panel's recommendations, which continued to promote the two standard solutions: consent and hospital efficacy.

In sum, the dim view taken regarding the capacity of the pre-June 2006 pool of deceased donors, and, the boundaries that were pushed to expand the pool are virtually absent from the information about organ donation that is publicly promoted. We see this below in an analysis of the 'discourse of donation' which is a social construction led by TGLN aimed at securing consent that is also taken up and advanced by organ donor advocates.

5.4 The Contours of the Discourse of Donation

Despite what medical experts are deciding, in the public realm the discourse of donation continues virtually unchanged over the period of 2000 and 2014. The impression given is that increasing rates of deceased donation is possible, and the means to this end is to increase consent to donation and hospital efficacy (the two standard solutions). In other words, more kidneys can be made available on the basis of the foundational rules governing organ transplantation in *Gift Acts*, reviewed in chapter 3. When DCD is raised, this is presented as another opportunity to donate, which it is. What is not raised is the possibility that refusals to consent may be legitimate and well-founded on the grounds, for example, that people take different signs as markers for the end of personhood. It is implied that consent signals a lack of generosity, not a disagreement over alienability.

This section analyzes the character and content of the ‘discourse of donation’ and shows who creates and sustains this discourse. Evidence used includes publicly available sources—websites, promotional material, and media—as well as interviews with organ procurement organization staff, transplant centre staff, and people directly involved as actual or potential donors and recipients, most of whom were also organ donor advocates.

5.4.1 The Moral Cause of Organ Donation

Organ donation is pursued as a government-sponsored public and moral cause similar to anti-smoking and other public health and charity campaigns. A senior staff member of TGLN interviewed for this study told me that, as in anti-smoking campaigns, “it is important that the government take a stand on donation to say that ‘this is what we do’” (OPO 1).

TGLN continually promotes organ donation through a number of means, including ongoing public relations methods and techniques standard to health promotion campaigns. A continuous flow of popular messages encouraging organ and tissue donation appears in brochures and posters made available at hospitals, doctor’s offices, and frontline provincial government offices where health cards and driver’s licences are renewed. Additionally, an annual *awareness week* is held in April. The TGLN website is regularly updated with links to other organizations and support for their organ donor awareness events. Volunteers regularly gather for group photographs with a green ribbon, symbolizing organ and tissue donation, which is reproduced as lapel pins, key chains, and printed on bags. The TGLN’s communications team is tasked with mounting successive two-year long multifaceted publicity campaigns.

The first major advertising campaign, which ran in 2005 and 2006, emphasized the urgency of organ and tissue donation as well as the plight of individuals on the transplant waiting list. Using

their new tagline, “every three days in Ontario someone dies waiting for an organ transplant,” the public was encouraged to initiate a family conversation about organ and tissue donation (TGLN, 2006:14).

The organ donation cause is driven by TGLN; however, *the cause* has a life far beyond the initiative and control of TGLN. It is taken up by a range of *actors*: independent advocates, healthcare professionals, academics, the media, pharmaceutical corporations, and insurance companies all participate in the reproduction of the discourse of donation. At an individual and institutional level, the networks leading to and from transplantation, as the moral cause of organ donation, are multiple and dense. Motivation for individuals to act as advocates for the cause is often derived from direct experience, being or knowing a transplant candidate, recipient, live donor, or *donor family* (family members of deceased donors). In this sense, TGLN is a leader and collaborator in the production of the discourse of donation, but not the only player. The TGLN creates and supports individual and corporate organ donor advocacy by sponsoring a volunteer network, cohosting events with corporations, and, most notably, defining messages through the production of publicity material for collective dissemination. As with its analogs in other jurisdictions in Canada and the United States, the TGLN is excellent at disseminating its message. Stories about organ donation in Ontario in the early twenty-first century are ubiquitous; rarely does a week pass without a report on some aspect of organ donation in a major Ontario newspaper.

In what follows, I detail the standard messaging provided to the public about organ transplantation following two major strands. The first strand is positive. It takes three forms: (1) a core message; (2) an emphasis on gift-giving; (3) gifts extended into legacies and dreams. I conclude this analysis of the “positive” by addressing a separate but linked narrative of the immorality of buying and profiting from the sale of kidneys. The gift versus market framework is

evident in this way of understanding kidney exchange in Ontario. The second strand is negative. It addresses organ donation as a *problem* with the core message emphasizing the shortage of organs. I deal with this separately, in section 5.5 below, in order to illustrate how the discourse of donation is deeply embedded in public policymaking.

5.4.1a The Core Message

The core message of organ procurement organization campaigns contains three aspects: (a) there is a need for organs; (b) transplantation is successful in saving lives; and (c) everyone can help alleviate the suffering of transplant candidates by simply consenting to organ donation. Stefan Timmerman (2006: 227) describes the need-for-organs plea as a “ritualistic recitation.” For example, a typical opening statement on an organ transplant website reads: “More than 4,000 Canadians are waiting for organ transplants and many Canadians die waiting” (CCDT, 2007). The most recent figure for patients waiting in Ontario, for all organs, is just under 1,500. Enumerating the number of patients waiting and relaying their dire need is commonplace.

Images are used as primary evidence to convey the success of transplantation. The TGLN’s annual report and website are filled with photographs of smiling recipients looking vibrant and often engaging in healthy activities like gardening or jogging. The secondary evidence offered is statistics showing one, five, and ten year post-transplant mortality rates. Don, a heart recipient I interviewed, made the success of transplantation the focus of his advocacy work. He sought to convey to the public that not only did he regain his ability to hold a job and contribute to society but that he could also achieve extraordinary feats. He made an example of himself by climbing mountains and trekking to the North and South Poles to promote organ donation, carrying signs saying “organ donation works.” Annual events such as the National and World Transplant Games

and organized sporting activities such as teams made up of transplant recipients entering dragon boat competitions serve to similarly promote organ donor awareness and publicize the health of recipients as evidence that *it works*. In this regard then, TGLN functions much like a charity. The goal is to increase rates of consent to donation by showing the public that organs donated are put to good use. It is worthwhile to give when you see the positive return and impact from giving.

To increase public awareness and education, TGLN's communication strategy is to buy advertising and to sponsor publicity events that disseminate key elements of the discourse of donation. There is continual outreach to religious communities, "to dispel myths about faith prohibitions to becoming organ and tissue donors," as well as Aboriginal and other cultural communities, the goal of which is to increase donations from Ontario's diverse communities (TGLN, 2009: 5). This continues a theme started in the Harris report which racializes blame. A volunteer program engages hundreds of people "spreading the word about the importance of organ and tissue donation" through speaking engagements, shopping mall booths, and local campaigns (TGLN, 2008a: 21).

A secondary school curriculum resource, called "One Life...Many Gifts," was introduced in 2008 to 220 high schools in twenty public and Catholic school boards across the province in order "to build a culture of donation among youth" (TGLN, 2009: 5). This resource would, it was hoped,

See youth take on organ and tissue donation as a cause that they can own. Our plan is that youth will transform Ontario's culture on this topic, as they have so successfully done in changing attitudes about smoking and protection of the environment (TGLN, 2009: 5).

In a departure from all of their other promotional literature, this resource uses the donors per million measurement and identifies not consenting to donate as illegitimate. Youth are told,

A future is yours to give. There is a crisis in Ontario. Every 3 days, someone in the province dies unnecessarily while waiting for an organ transplant...The donor rate in Ontario is only 13 donors per million population, less than half of what it should be. That means that people who could live – if they had a new heart, lung, liver, kidney, pancreas or small bowel – sit on a waiting list, hoping for a donor. That wait is often in vain.

Every day, Ontario families experiencing heartbreaking tragedy are asking about donating the organs and tissues of their loved ones who have just died...It takes great courage to reach out and help someone else when you are in deep distress yourself. The valour and grace that are unspoken attributes of donor families are worthy of our deepest admiration. However, sometimes families choose not to donate. It may be because they don't understand the process, because they had never discussed donation, or because they did not know the wishes of their loved one (TGLN, 2008a: 2-7).

All other materials cite the severity of the problem using the tagline that “every three days someone dies waiting” and the number of people waiting. By 2010 organ and tissue donation education became mandatory in high schools in Ontario. Students are told that this education, “...can help you make a real difference in society” (TGLN, 2008a: 7).

Other activities include an Annual National Organ and Tissue Donation Awareness Week and publicity events such as concerts and Living Green Ribbon events where people wearing green ponchos are formed into a ribbon for an aerial photograph. On the technical side, an affirmative electronic registration consent system was put into effect in 2008 with online registration available starting in 2011. Registering advanced consent to donation was promoted by a publicity campaign called, “Register ‘Yes’.”

In every form of communication, the public is told that everyone can help by consenting to organ donation, referring to advanced consent for deceased donation. Linking the population to individuals, the public is told that indicating consent to organ donation is sufficient to save the lives of transplant candidates. One piece of a recent multifaceted campaign launching online registration to consent is a TGLN video titled *Asking Too Much* (TGLN, 2013c). It dramatically

synchronizes punchy sentences and illustrations to powerful orchestral music. Viewers are told this request is logical, noble, and supported by the world's major religions. They are not being asked to give money or run a marathon; rather, the TGLN's request is:

For your understanding, your compassion, your reason. At this moment in Ontario, 1,500 people need a life-saving transplant. *Every three days, one of them dies. But they don't need to. Why? Because it only takes two minutes to help them.* So, all we're asking you to do (finally!) is register your consent for organ and tissue donation at beadonor.ca. As an organ donor, you can save up to eight lives. That means that you could be a hero eight times over. Not bad, eh? So, are we asking too much? We don't think so. And there are 1,500 people out there, right now, who hope you think the same. Thank you. Register now at beadonor.ca. (TGLN, 2013c)

Offering a *death metric* of one death every three days, insisting that such deaths are avoidable and that registration to advanced consent will save a life and create heroes is highly-crafted hyperbole. Missing in this formulation is the most crucial piece: the need for donors to die. By contrast, death—and the rarity of *the opportunity* to donate—is mentioned in TGLN's companion "Gift of 8 Movement" campaign not as a hindrance to organ supply, but additional reason for advanced consent:

A donor can save eight lives. . . . Because the opportunities for organ donation are relatively rare and the impact is life-saving, it's important that Ontarians give serious thought to organ and tissue donation and register their consent to donate. By registering, you are essentially making a decision to help save lives, if you are able, after death through organ and tissue donation. By making this decision, you give hope to patients waiting for a life saving or life enhancing transplant and their families. (TGLN, 2014b).

Death, saving lives, and giving hope are established as the reasons people must think about and make a decision regarding organ donation.⁴⁷ This dual campaign works partially on guilt, by

⁴⁷ This companion campaign invites individuals and corporations to sponsor localized workplace or municipality-based efforts to reach registration targets by soliciting friends and members of their social media or employment networks. It operates on the same model as province-wide charity fundraising drives in publicly displaying results to foster friendly competition.

encouraging empathy with transplant candidates, and partially on affinity in encouraging the public to join a cause greater than themselves: the cause of saving lives.

Electronic registration provides TGLN not only with a new tool for convincing families to consent to organ donation but also a new *metric* for measuring and continually exhorting public support. Registration rates can be statistically generated to examine correlated variables. Geographic competitiveness is encouraged, with maps produced to illustrate areas of the province with higher and lower consent rates.

For instance, a map in 2010 in the *Toronto Star* provides a sense of the public uptake of the cause of organ donation. In the online comments section of the article, Charlotte Babbage wrote, “I took thirty seconds and sent an email to everyone in my office with a link to the *Star* article and a link to The Gift of Life site. If one person at every work place did that, imagine the possibilities.” Another commentator, named Joanne, posted: “Ridiculous! It’s not hard to do, signing your organ donation card and [you] could save your own friends, family or neighbours. Come on, people!” (*Toronto Star*, 2010). Public exhortations of this kind are a logical extension of the discourse of donation produced by an array of organ transplantation and donation advocates in Ontario. But what these members of the public express is no longer positive, it is aggressive.

5.4.1b Organs as Gifts

A second layer of messages presents transplantation as a miracle. In these tropes, donors are heroes, and recipients are forever grateful. For example, TGLN annual reports are filled with recipients expressing gratitude through short quotations, longer narratives and, in some years, holding signs that read, “it works” and “thank you.” Recipient testimonials, referred to as “stories of hope,” are offered on the TGLN website to inspire consent registration. Rizwana Ramzanali, a

kidney and pancreas recipient in 2004, is quoted: “After 28 years as an insulin dependent diabetic, of which seven years were spent on dialysis, my life changed when I received the Gift of Life in August 2004 [...] I am forever indebted to my donor family for consenting to donate the organs of their loved one” (TGLN, 2014c).

Even the individual decision to donate—and sharing this with one’s family—is described on the TGLN website as “the best gift” (TGLN, 2014e). A testimonial by a “Donor Mom” captures the positive feelings for the donor family in giving a gift: “My son had a very dry sense of humour. He would say: ‘Well mom, you know, organ donation is really just the ultimate recycling program!’ We were just so proud to be able to carry out his wishes. Thirty-five people benefited from Andy’s gift” (TGLN, 2014e) .

Often the act of expressing gratitude to an anonymous, deceased donor for the gift of an organ takes the form of advocacy for organ donation. Denis J. Segatto, a kidney recipient in 1979, writes:

I have never forgotten the gift of life I received, and have tried to give something back in return: I have volunteered with the Kidney Foundation Windsor chapter and the Trillium Gift of Life Network, and I cofounded the Pulse Support Group in 1989 with three other transplant recipients. Pulse promotes organ and tissue donation (TGLN, 2014f).

Similarly, one of my interviewees, Pete, a deceased donor kidney recipient, described his devotion to promoting organ donation within his labour union as “the least I could do” to thank his donor. Ironically, the promotion of organ donation conceived of – and genuinely pursued – in honour of donors serves the interests of (potential) recipients. In my interviews, this did not seem to occur to the recipients who volunteered their time to do this kind of advocacy work. I found it inappropriate to suggest that their pursuit of *the cause* was admirable and yet unintentionally self-serving.

In another example from the TGLN website, Joanna, a mother whose infant received a heart, raised a collective insurance and fairness logic. She is quoted on the TGLN's "Be a Donor" website saying: "If you needed an organ, would you take one? If you would...why wouldn't you share yours to save somebody else's life? It makes you a hero" (TGLN, 2014g). In this formulation, being part of the community that receives requires fulfilling the obligation to give.

5.4.1c Legacies and Dreams

Organ donor awareness also has a life of its own, one that is connected to TGLN but also independently pursued. Thus, TGLN informs but does not control organ donor awareness messaging. Regular media attention and independent advocacy work—especially independent campaigns—are very common. Here the core message remains the same: organs are needed, transplantation is successful, and you can help by consenting to organ donation. In newspapers such as the *Toronto Star*, the positive framing of organ donation can mean annual multi-page features of transplant candidates who are on waiting lists and the miracle of change experienced by recipients. Human-interest stories of transplant candidates and recipients, especially children, aim to instill the recipient-centric orientation of the discourse of donation by keeping the public aware of the need for organs.

A number of independent campaigns promote organ donation as part of the discourse of donation. These campaigns usually centre on a particular individual, either featuring a transplant recipient or memorializing a deceased donor. George Marcello began his Torch of Life campaign in 1997, trekking across Canada and hosting publicity events in every town and city along his route, "after receiving a lifesaving liver transplant" (The Torch of Life, 2014). A message is repeated throughout Marcello's website: "Every day people die unless they receive an organ. We

can change this.” In 2001, the Torch of Life was blessed by Pope John Paul II, “who called organ and tissues donation a Genuine Act of Love and encouraged young people to carry its message” (The Torch of Life, 2014). As part of the Torch for Life, an actual torch is carried by different young people in an ongoing series of *treks* across Canada.

Macdonald (2009) details a standard organ donation event, this one at a downtown Toronto high school in 2004 featuring Kristopher Knowles, a then fourteen-year-old potential recipient. *Trekkers* are met and escorted to a venue for speeches in which the key individual conveys his/her story, followed by politicians. The climax on this occasion was the speech called “Kristopher’s Wish.” In it, Kristopher told a high school assembly about the reason for his trek: “this is my dream: that every man, woman and child on the list should get an organ and that everyone should sign their organ donor card” (Macdonald, 2009: 281). Ontario’s Minister of Health, George Smitherman, then told students, “You too can take power over your health. *You* can make this a more healthy society. By not smoking, not drinking and driving, not eating too much, exercising—and signing your donor card!” (Macdonald, 2009: 280).

In 2012, Kristopher, now twenty-two years of age, resumed trekking, this time with then Torch of Life bearer Khaled Khatib. Here the power of organ donation to bridge divides was brought to the fore. A local Ontario newspaper, *Kincardine News*, in the town of Kincardine, reported that Khaled, a Palestinian, was campaigning on behalf of his younger brother, a deceased organ donor who, the report states, was “accidentally, fatally shot by an Israeli soldier” (Sutter, 2012). In response, “Khatib’s family made the unlikely decision to donate Ahmed’s organs to Israelis, eventually saving five people with organ transplants” (Sutter, 2012). This particular act of publicizing an organ donation to memorialize Ahmed is presented as more heroic and moral than usual, with organs symbolizing gifts given to forgive and make peace. The newspaper reported

that Kristopher and Khaled were greeted by a crowd of cheering high school students and the mayor who “vowed to promote organ donation” in the town (Sutter, 2012). The article concludes by noting that the Torch of Life campaign has received letters of support from Prime Minister Stephen Harper, Premier Dalton McGuinty, and Toronto Mayor Rob Ford. This case in particular exemplifies how the celebration of organ donation draws attention to the positive in a way that deflects attention from questions about whether the soldier in this story was held to account for killing a child.⁴⁸ The heroic act displaces inquiry regarding the complex conditions of its making. A rally for organ donation is non-controversial whereas a rally to address the prevention of death by injury or war is controversial. What is at stake is the threat of valuing the exchange ahead of the population of organ donors.

Other organ and tissue awareness campaigns similarly memorialize deceased donors. For example, each with their own websites, publicity and media coverage, “The Victor Davis Memorial Ride” is organized by the brother of an Olympic swimmer who died suddenly, and, “Outlive Yourself” is a cross-country bicycle trek organized by a friend of a young man who died while waiting for a heart. A prominent campaign called “Sandrine’s Gift of Life” ran for over five years. It memorialized Sandrine Craig, an eleven-year-old girl who died in a 1999 school bus accident. Her mother donated her organs to “save or greatly enhance” the lives of six individuals, including three children. The website explains:

Our goal is simple: inspire more people to talk to their family about their wishes about organ and tissue donation. That simple act, which doesn’t even cost a cent to do, can save lives. History shows that if you sign your donor card and tell your family about your feelings, in most cases the family respects those wishes. However, if you haven’t relayed your wishes to your family, *even if you have signed*

⁴⁸ Attention is also deflected from questions about deceased donor organ allocation such as whether all the child’s organs going to Israelis was truly chosen by the family (and is that fair?), or was the recipient pool influenced by issues of access to healthcare that may disadvantage Palestinians or other non-Israelis?

a donor card, in half the cases, the family will say no to transplantation because they wonder if that's what their loved one really wanted. Just think how many lives are wasted needlessly.

As Sandrine's mother, Diane Craig, says over and over again, "we're burying the cure."

Sandrine could have been from anywhere in the world. She could have been your daughter, sister or niece, granddaughter or friend. Most importantly, the people who received her life-saving organs could have been someone you loved...or even yourself.

You never know when you might need a transplant. A sudden virus could affect your heart. Liver disease could strike fast and furiously.

The cure is easy!

Thousands of people around the world die needlessly each year because they never received a much-needed organ or tissue in time. Yet, it is so easy to change that tragic waste. All you have to do is download the donor card, sign it, and most importantly, talk to your family! (Craig, 2009)

The campaign encourages others to take up the cause and launch their own local awareness campaigns. Diane Craig, Sandrine's mother, explains why she established the campaign.

It gives Sandrine's life, and mine, a purpose.

Sandrine's legacy not only helped the lives of six people, but offers hope to the over 3,000 people waiting for transplants in Canada. They wait for kidneys, for lungs, for hearts. They wait for eyes to see. And the cure is there to be had.

'I want organ donation to become the right social thing to do,' says Diane. 'Not doing it should be as unacceptable as drinking and driving. There are so many people who are waiting...and we're burying the cure.'

The body is the tool that we use to carry the soul. Who a person is, is their mind, their spirit. And out of something so tragic as losing a loved one, something wholly good can happen. (Craig, 2009)

As Macdonald (2009) argues, such memorializing practices do more than raise organ donor awareness; they are also spiritual and moral practices. Grieving family members are engaged in meaning-making by turning their decision to consent to organ donation into a public campaign.

In spite of the millions spent on formal publicity campaigns, it was reported in the media that the sudden rise of a captivating individual recipient can result in more website visits or registrations of consent to organ donation in Ontario. For example, *www.alungstory.ca*—a website dedicated to H el ene Campbell’s wait for lungs—launched around 2011 caught the attention of American talk show host Ellen DeGeneres. Post-transplant, H el ene appeared on the show to dance with Ellen. The federal Minister of Health, Leona Aglukkaq subsequently (and has repeatedly since) posed with H el ene to announce funding for transplantation. Similar contact moments with celebrities make the continual efforts of ordinary people promoting organ and tissue donation awareness newsworthy.

In 2012, Facebook added an *organ donor* category for people to add to their public personal profile to show to their contacts that they have consented in advance to donate their organs at death. This opportunity for self-declaration through a social media site establishes “donor status” as a marker of personal and moral identity. As with the independent campaigns and high school rallies, all of these offers to join the cause of organ donation constitute an affinity route to gain consent to donation. They invite the public to affiliate themselves with a positive change. What is notably absent is any assertion of donor protection; this is assumed.

5.4.1d Immoral Organ Acquisition: Buying Is Wrong but Understandable

Lastly, there is a separate but linked narrative about immoral transplantation: buying kidneys, and profiting from their sale. My research found suspicions but no evidence of monetary transactions between donors and recipients in Ontario or Canada. As described in chapter one, Ontarians, however, are buyers of kidneys in other jurisdictions, most often in countries of origin or heritage (G.V. Ramesh Prasad et al., 2006). When transplant tourism reports started to surface, a Canadian

Broadcasting Company editorial claimed that a “shameful” lack of citizen generosity and medical system inefficiency are to blame for “the shortage crisis” and, even thereby “*encourage* a black market,” (CBC, 2005, emphasis added). Organ donor advocates I interviewed wanted nothing to do with this topic. They had little to say, generally distancing themselves and expressing fear that the international organ trade might tarnish the cause of organ and tissue donation.⁴⁹

Canadian and international media tend to cast the choice to buy an organ abroad as immoral, yet perhaps understandable because of the organ shortage (see for the WHO, Garwood, 2007). The tone of condemnation is sympathetic. As stated by the CBC (above) given “our” failure to provide organs for our own people, it is understandable that transplant candidates would buy outside the country. In 2012 and 2013, the Toronto International Film Festival featured documentary films by Canadian filmmakers on the organ trade. A CBC current affairs radio show interviewed the 2013 filmmaker, Ric Esther Bienstock, as part of their “Line in the Sand: Dilemmas that Define Us” series (CBC, 2013). The pivotal debate was whether buying a kidney was ethical, specifically hinging on whether the seller gained from the transaction. As we see in the following sections, there is a more relevant *line in the sand* that is not in public view.

In this section, I argued that there is a dominant public knowledge that shapes thinking about transplantation through a morality of need, of giving, and of possibilities; to deny this common sense knowledge is deemed *wrong* by society at large. Borrowing Metzl and Kirkland’s (2010) thinking about health, one cannot be *against organ donation*. Debates are limited as to how to

⁴⁹ Similar fears were expressed by several donor/recipient interviewees when asked about movies and television episodes on the topic of organ transplantation. They did not care for the sensationalization of transplantation and judged cultural productions on the basis of whether the overarching message supported donation or not.

procure consent at an individual and system level. As we see in chapter 6, this form of knowledge stands in stark contrast to competing explanations where supply and demand are seen as dynamic.

Within this strand following the social construction of meaning attached to organ exchange from deceased donors, the lack of transparency about all of the ways in which lines of demarcation are being pushed and changed is striking. Calls and efforts to change the rules regarding consent are debated in the public realm but actual changes made to the rules regarding diagnosing death in 2006 are made by experts. Yet, we need to remember that this division between what is visible and what is less visible is not insidious: diagnoses are the domain of experts and how these changes came about reflects the broad scope of authority originally granted to medical authority. Nevertheless, the effect is to skew public understanding of what variables are most important.

5.5 Organ Donation as a Problem

A second major strand in framing the ‘discourse of donation’ takes a negative stand, addressing organ donation explicitly as the problem of organ shortage. I review this dimension in conjunction with discerning how this discourse is part and parcel of policy recommendations. In the next chapter I pull out of these reports the same caveat used in the Premier Harris report of 2000 that warns that when the pool of potential donors is taken into consideration, the emphasis on the two standard solutions (which are efforts) may be futile.

Again, deceased donation is the exclusive referent in this discourse. In this framework of meaning, nations are compared, numbers produced, and Canada is shamed. Chastising, problem-identification, and alternative action take the place of positive encouragement to donate. For example, The Canadian Council for Donation and Transplantation (2007) states that “donation rates in Canada are stagnant and waitlists for transplants continue to grow.”

During the period under study, journalists, newspaper editors and politicians have addressed the problem of the organ shortage. Journalists, such as *Globe and Mail* columnist Andre Picard, frequently write on the topic. For example, in 2007, Picard covered the speech of Dr. Phil Halloran, a transplant surgeon, at a meeting of the Kidney Foundation of Canada:

What he said, quite bluntly, is that almost 1,200 Canadians a year who needed life-saving organs didn't get them because of the failings of our transplant system. 'This is a scandal,' he said. He's right: It is a scandal... (Picard, January 18 2007: A1)

Picard reiterates Dr. Halloran's presentation of the difference in donor rates between the United States and Canada but mentions that one explanation for different deceased donor rates is more guns and hence more brain deaths in the United States. He follows this note with the speaker's response, "Dr. Halloran dismisses those arguments as nonsense. 'You can arabesque around this all you want, but the bottom line is that it's an organizational issue,' he says" (Picard, January 18 2007: A1). Halloran's main point, as reported by Picard, is that Canada has lower rates of donation, which is costing us lives, because of the absence of a centrally coordinated network like in the United States. The solution is to replace provincial/territorial organ procurement organizations with a single federal agency that has power, a national mandate, and a substantial budget (unlike the Canadian Council on Donation and Transplantation, in place at the time of Picard's writing).

The shortage is a vexing problem. The system has failed to achieve the numeric goal set by Premier Harris. The message is that donor rates should rise, that Ontario ought to be able to achieve the same donor rate as other jurisdictions, and, with more patients in need, this is a growing crisis.

5.6 The Impact on Public Policy, 2007 onwards

As TGLN's publicity campaigns and independent campaigns to raise organ donor awareness bring the issue of organ donation into the public mind, a range of politicians take up the cause. In this section we see that what bears greatest influence on public policy in Ontario during this period is the discourse of donation. This is most evident in the 2007 and 2009 public policy reports on the problem of how to increase Ontario's deceased donor rate. In keeping with the campaigns, the shift behind the scenes among experts to expand the pool of potential deceased donor by changing donor eligibility criteria to include Donation by Cardiocirculatory Death (DCD) is taken as fact. We also see continued reliance on the DPMP measure with the added caveat.

5.6.1 The 2007 Ontario Citizens Panel on Increasing Organ Donations

Even with an upward trend line starting in 2006, the progress made and the pace of increasing organ donation was considered by many politicians to be insufficient. Four private member's bills addressing the organ shortage were introduced in the Ontario provincial legislature in 2005 and 2006. Solutions focused on consent: proposing *mandated choice* (which requires Ontarians to declare "yes" or "no" to organ donation upon acquisition or renewal of provincial health insurance or driver's licenses), or removing the need for explicit consent altogether by changing to a presumed consent regime. Thus, just as DCD came into force as the new diagnosis for death, public attention was drawn to the issue of consent to organ donation which now became characterized by the assertion of a right to donate.

Like former Premier Harris, Ontario's Minister of Health, George Smitherman decided to champion the cause of organ donation. Smitherman appeared at campaign events, as we saw above, and, in 2006, declared the need for another investigation into the organ shortage, this time regarding whether to change the altruistic rules of consent from explicit consent to presumed

consent. According to a key informant, Smitherman was convinced that presumed consent was the “magic bullet” that would resolve the organ shortage (OPO1).

Over the winter of 2006–2007, a panel was established to hear the voice of Ontarians on the organ shortage question. Following forty-five public meetings and twenty-nine discussion groups, the Citizens Panel report found a lack of support for presumed consent.⁵⁰ This unexpected outcome shifted the focus of the Citizens Panel report to a focus on the rights of individuals in advanced consent to organ donation and recommend an electronic registry replace organ donor cards.

The report of the Citizens Panel on Increasing Organ Donations (hereafter the Citizens Panel report) thus carries a tone of indignation that individual consent recorded on organ donor cards is not effective in guaranteeing organ donation. According to the report,

[people] believe this will guarantee [that] their donation wishes will be respected in death. They were shocked to learn that *donor cards are almost never seen or asked for*, and that the family’s decision will prevail even if it contradicts the deceased’s wishes (Ontario, 2007: i, emphasis added).

Here we see that exhortation becomes imbued with rights language pitting individuals against families with respect to ownership of the valuable organs and tissues of a dying person. This is known as the problem of the family veto. The message conveyed is that an offence is committed when individual donation wishes are not respected. Whereas in 2000 media reports reassured the public that organs would not be taken without family consent, now the individual and the family were at odds. One’s family was no longer an ally ensuring donor protection against the threat that organs are valued ahead of persons; this threat has disappeared. What is important is to protect potential donors from the risk that their family denies their right to donate.

⁵⁰ This finding reaffirmed survey results reported in the 1985 report.

Where the pattern set by the Harris report is repeated is in the caveat regarding the size of the pool of deceased donors. This disclaimer, integrated into the text of the report and absent from recommendations, acknowledges that the problem of the organ shortage may not be a result of “system failure” (Ontario, 2007: 10). Showing some of the Panellists’ research, an assessment of the availability and limits of each type of donor—brain dead donors, DCD donors, and living donors—is made. Brain dead donors are shown to be declining over the past thirty years, shifting in diagnosis from motor-vehicle accidents to industrial, sports, gunshot, or suicide injuries. “It is important to understand that there is *an absolute limit* to the number of donors who suffer brain death [...] less than 1% of those who die in hospital each year” (Ontario, 2007: 13, emphasis added). The report reviewed reasons for the decline, highlighting the good news story of decreasing stroke and motor vehicle accident rates. Panellists stated that the size of the pool of brain dead donors must be taken into account:

Some other jurisdictions with higher donation rates have much higher death rates from the most important source—CVA [cerebrovascular accident]. Some have tremendously higher rates of death from motor vehicle accidents, motorcycle accidents and gunshot wounds. Some have younger demographics with more men working in heavy industry. *They have more brain dead patients, so can get more donors, but they are not to be emulated.*

The message in the numbers is clear. *Donations from the brain dead cannot meet the need* even at the Panel’s suggested goal. Even to get to this goal will require the serious system reform the Panel recommends in this report. *And it will require realistic expectations based on our health facts in Ontario. Failure to do so will ensure a permanent inability to achieve these goals and the resultant assignment of inappropriate blame* (Ontario, 2007: 13, emphasis added).

For this reason, the report’s recommendations were based on conversion rate, not donors per million population. Even in recommending that a 75% conversion rate be adopted—doubling the

then current rate in Ontario—the Citizens Panel report acknowledged that “no one knows if this is actually achievable in Ontario” (Ontario, 2007: 13).

The Citizens Panel report acknowledged limitations in knowledge about the size of the deceased donor pool and that Ontario may not be comparable to other countries like Spain. Panellists even stated that “it is unlikely that Ontario ever will reach the donation rates of some other jurisdictions, nor would it wish to have that many brain-dead patients” (Ontario, 2007: 13). Thus, assessing the donation system by using deceased donors measured per million population as a comparison measure was implicitly accepted as flawed and unfair. Instead of consistently ranking Ontario below other jurisdictions, “the Panel suggests that *perhaps any increase should be considered a sign of success given a relative decrease in the sources of organs*” (Ontario, 2007: 10, emphasis added).

The emphasis on consent for deceased donors is then explicitly shown to be a logical deduction, “since the numbers of brain dead patients is limited and once a patient is a donor, efficiency is high, an increase can occur only if more of these patients actually become donors” (Ontario, 2007: 12). The report also claimed that Ontario needed to turn to new sources of organs. Donation after cardiac death was explained without mention of the lack of agreement among professionals that DCD constitutes death (see Doig, 2006). This specific donor pool “could increase the number of donations by up to 25%,” but it was recognized as having “a definite limit to its growth,” whereas living donation “could be expected to dramatically reduce the waiting time for kidney and liver transplant” (Ontario, 2007: 13). As we see in the next chapter, dissent among experts that DCD constitutes death is not mentioned in the report (see Doig, 2006).

In response to the Citizens Panel report, the Ontario government made three new investments. First, to allow TGLN access to Ontario Health Insurance Plan consent to donation

information. This led in 2011 to a new affirmative electronic registry. Key informants told me that this approach to electronic registries follows best practices tested at American OPOs. By recording only ‘yes’, not ‘no’ to consent, TGLN Donor Co-ordinators can still ask the family for consent (OPO 2). Dubbed the ‘nudge’ to consent, the registry is used not to deny family veto but to convince families to agree. For this reason, knowing ‘no’ is not helpful. Second, to provide an additional 10.4 billion dollars to hospitals over two years for organ donation costs. And, third to create a living donor database to match incompatible pairs. As we see in chapter 8, this initiative is taken up in the Living Donor Paired Exchange program managed by Canadian Blood Services at the federal level.

Based on my interpretation, the power of the recipient-centric discourse of donation is evident in the public policy that results from this report by the Citizens’ Panel. Even though this report recognizes the size of the deceased donor pool as a limitation more explicitly than any other, the impact of this recognition is nil. Organ exchange continues to focus on the two standard solutions, consent and hospital efficacy.

5.6.2 The Ontario 2009 Report

By 2009, the problem of the organ shortage is nuanced by the idea of failed justice—unfair wait times for transplant candidates—and normalized within a larger healthcare wait times problem. Two years after the Citizens Panel, the province of Ontario began producing target wait times for various medical services with the aim to monitor and reduce wait times for key health services. In 2009, an Organ and Tissue Transplantation Wait Times Expert Panel produced a report containing twenty-six recommendations, which repeated the same themes of earlier organ exchange reports: the need for more public awareness, more medical staff awareness and

education, stricter requirements for hospital participation, more money, and equitable access to organs. The emphasis here, however, was on setting performance targets, establishing both system oversight and publicly posted wait times by organ.

The 2009 report quickly established the problem that too few organs were available. A tone of entitlement characterized the report, which states that, “Ontarians usually wait unacceptably long periods of time for an organ” (Ontario, 2009: 2). The report declares that,

Unfortunately, if a person in Ontario needs an organ transplant today, there is a very good chance that he or she will wait a long time with about 1,700 other people or die before an organ becomes available (Ontario, 2009: 4).

And repeats the TGLN tagline, “Every three days, someone on the organ transplant waiting list dies” (Ontario, 2009: 4).

Section seven of the report addressed the availability of organs for each type of donor. However, this part of the report was characterized by a superficial presentation of data absent of analysis, especially the data on donors. The authors glide over the statistical figures and tables with a consistent narrative of the discourse of donation, underscoring the importance, regardless of evidence, to *do more*.

The first figure shows significant variability in Ontario’s deceased donor per million population rate over a ten year period. Rather than investigate the reasons behind the variability, three morally-driven, selective claims were made in bold print about the rate of donation per million population: (1) it remained steady instead of “keeping up” with the growth of the population; (2) it was below the Canadian average in 2005; and (3) it varied dramatically by region (Ontario, 2009: 11).

The next paragraph noted that Canada's deceased donation rate per million population is lower compared to most other Western countries. Rates were given per million population for 2005, with Canada at 13 compared to 35 for Spain, 25 for Austria, 24 for Belgium, 22 for France, 21 for Italy, and 25.5 for the United States. Worse, "in 2008, the US rate was 27.8 PMP compared to 14.1 PMP in Ontario" (Ontario, 2009: 11). However, what is by now a standard caveat to justify an admittedly flawed comparison is then offered:

International comparisons must be used with *caution* since a common definition of "number of donors per million population" does not exist [...] Although different methods are used to calculate donation rates, *it has been concluded* that several countries consistently have high rates of donation: Spain, Austria, Belgium, Norway, France, Switzerland, Portugal, Italy and the United States (Ontario, 2009: 12, emphasis added).

There was no further defence of the validity of the comparison in spite of the rejection of such comparisons by the 2007 Citizens Panel. Nor was there any analysis or review of studies (such as Healy, 2004, 2006d) to explain why other countries consistently have high rates of donation. The point then can only be a moral one, which is the assertion that Ontario is failing compared to other jurisdictions.

With respect to organ donors, the analysis in the Citizens Panel report is superficial. This section starts by reviewing the number and type of organ donors as either living or deceased. The Panel identifies the increase in the donor rate as mostly attributable to more living donors, as well as organs (from deceased donors) imported from other provinces and the United States. A figure was then given that illustrated that causes of death for deceased donors had gradually shifted over time: "From 1999 to 2004, the proportion of donors who died due to trauma from motor vehicle collisions has decreased. This is due to stricter laws on impaired driving, speeding and use of seat

belts and vehicle air bags” (Ontario, 2009: 14). While this is an acknowledgement of the link between injury and organ donation, it is tokenistic. It is not clear why experts—unlike the layperson-led Citizens Panel report—excluded analysis of the size of the pool, particularly the research finding that it had decreased in overall size (such as David Baxter’s studies that were identified in the introduction and TGLN data that was just starting to become available), or the kind of more nuanced analysis possible using TGLN conversion rate data (as provided in chapter 6). The inclusion of donors is therefore benign in effect and easily ignored. And attention was quickly refocused on consent with the next paragraph stating that “ethno-racial factors may impact the decision to donate” (Ontario, 2009: 45). Finally, one and a half pages was devoted to showing a 50% conversion rate at 21 priority hospitals and a 75.6% rate for all hospitals lifted directly from TGLN’s annual report.⁵¹ The report positively noted that, “Ontario’s conversion rate is higher than a United States average conversion rate of 71.1%,” but no explanations were offered for the observed 20% difference in conversion rates between American and Ontario OPOs (Ontario, 2009: 16).

Throughout section seven of the 2009 report, the loose narrative repeatedly drew attention to how Ontario’s donor rate was failing compared to other jurisdictions. But the evidence-base is weak and there is no effort to decipher why Ontario pales in comparison.⁵² By including—but dismissing—measuring the pool of potential deceased donors, the expert panel failed to account for the central piece in their analysis: what explains the deceased donor rate in Ontario? In exactly the same fashion as Nowenstein’s example (noted in the introduction), the panel asserted a moral

⁵¹ TGLN categorizes these 21 hospitals as Tier 1 hospitals.

⁵² This is especially given that the figures presented show contradictions in the numbers and positive if modest increases in Ontario’s donor rate.

position, stating that this situation is wrong instead of offering or even suggesting empirical investigation, as Premier Harris' and the Citizens Panel reports had done. Recommendations assume that the reason for the current donor rate is a result of either consent or hospital efficacy.

The report consistently underscored the importance of encouraging a culture of donation in the society at large and within hospitals specifically. The idea of establishing a standard wait time for a transplant denies that an organ is any different than any other type of 'medicine,' such as dialysis. For critical scholars, this denial reflects the hypocrisy of *gifts* used to conceal utilitarian logic. Establishing an expected wait time for a gift can be interpreted using Godbout and Caillés' (1998) conceptual framework to epitomize the clash that occurs in mixing the *gift* world and *state* world. It signals acceptance by the state that receiving an organ from a deceased donor is an entitlement of citizenship that ought to be provided according to the agreed upon wait time. Such entitlement claims *for* recipients are made in spite of retaining the conceptualization and exhortation of organs as gifts. The 2009 Wait Times Report thus reflects the kind of disjuncture between rhetoric and reality described in the introduction that social scientists have observed over several decades.

As a result, and in keeping with previous reports, the emphasis on the needs of potential recipients ignores organ origins. A genuine calculation of a standard wait time for a deceased donor organ would need to include calculations for the size of the donor pool, starting with the rate of strokes and injuries, for example, that lead to catastrophic neurological conditions and rates of survival. But measuring the deaths required to meet potential recipients' need for organs might undermine the ways organ donation is conceptualized. Through the imbalance in what appears in the report and what does not, the humanness of where organs come from is lost in the production process, in spite of – and because of – the exaltation of organ donors within that process. The effect

of the indirect claim that recipients have a right to an organ provided by the government is to again obscure organ origins in a way that reflects a ‘structured forgetting’.

5.6.3 The Discourse of Donation in Public Policymaking

The table below illustrates a number of key patterns in the framing of the problem of organ supply and proposed solutions in Ontario public policy. The first column identifies the evidence presented to demonstrate that increasing the donor rate is possible. After 1985 an international comparison using the DPMP measure is used to claim that Ontario can do better. The primary means in each report is to invest in aspects of conversion that fall into the two standard solutions: consent and hospital efficacy. Solving the organ shortage uniformly relies on two standard solutions: consent and standard hospital efficacy. Each report calls for more exhortation, referred to as public awareness and education to consent to organ donation, and medical provider awareness and education to perform the tasks of organ procurement. Each report’s unique recommendations also fall into these two solutions. The 1985 report called for the provincial government to invest in deceased donor organ acquisition to enable kidney transplantation as a therapeutic modality. The 2000 report was more specific, calling for a provincial OPO and new hospital rules enabling OPO intervention in the dying process. The 2007 report identified enforcing individual consent against the family right to veto advanced consent. The 2009 report promoted a culture of donation.

Table 12 *Summary of Special Reports on Organ Exchange, Ontario, 1985–2009*

Year	Evidence increase is possible	Primary means ⁵³ to solve the problem	Size of donor pool	Number of deceased donors/yr ¹	Target

⁵³ Since all reports call for more public and healthcare provider awareness and education, the primary means identified here are the means, in each report, that go beyond this general call.

1985	Potential donor estimate	Invest	Assessed	139	Triple: 75 PMP in 20 years
2000 <i>Harris' report</i>	DPMP compared	Establish an OPO and hospital rules	Recognized unknown	140	Double: 300 in 5 years
2007 <i>Citizens Panel report</i>	DPMP compared	Enforce individual consent over family veto	Recognized unknown	170	75% conversion rate
2009 <i>Wait Times report</i>	DPMP compared	Promote a culture of donation	Not included (only characteristics)	182	None set

1. The numbers cited in the table are taken from each report and are higher than the TGLN, TOTAL database numbers used in chapter 4. The one exception to this rule is the 1985 Report where deceased and live donation are not distinguished and the figure, 265, is so significantly different that for comparison I use the TGLN TOTAL database figure.

The middle column identifies whether the size of the deceased donor pool is included in each report. Here we see a shift from an assessment included in the 1985 report, to recognition that the size of the potential pool is unknown in 2000 and 2007, to the disappearance of any mention of this matter in the 2009. Thus in the three Ontario reports reviewed here there is a move away from evidence supporting the underlying claim that it is possible to increase the number of deceased donors. Even though, by 2007, TGLN had produced a conversion rate to serve as their performance metric instead of DPMP, this measure and its detailed data elements are ignored in the 2009 report. Public understanding of the factors that enable deceased organ donation is thus channelled to focus on the two standard solutions rather than through a presentation of meaningful data and explanations.

The table shows that, excluding 1985, the number of deceased donors cited in each report rises from 2000 to 2009. At the same time, ambitious targets, missed every time, are lowered from tripling the donor rate (1985 report), to doubling it (2000 Harris' report), to reaching a 75% conversion rate (2007 Citizens Panel report), and then not setting a target at all (2009 Wait Times report).

5.7 Sources of Blame

In speaking with key informants in Ontario, the overwhelming majority were loyal to Ontario's altruistic system. Not surprisingly, blame for low deceased donor numbers was laid on either a lack of public generosity and/or hospital in efficacy. Organ donor advocates who volunteer for Ontario's organ procurement organization, Trillium Gift of Life Network, told me that people do not want to talk about death. Maureen, an interviewee who donated her kidney to her brother and later became an organ donor advocate, said, "it's not because people don't believe in [organ donation]. If you ask them, the vast majority say 'yes,' [but] they don't tell their families, they don't do anything active to make it happen." And, unwillingness by families to consent, in the context of a difficult situation, was another reason blamed for the organ shortage.

The nationalist/provincialist narrative identified earlier also accompanies the idea that consent to donate is the reason for the organ shortage. The same interviewee, Maureen, further explained that, "...we're behind. We're so very far behind. Canadians' donation rates are really, really low." These accusations are cautious not to directly disgrace individuals or families, but it is taboo to publicly state that one is against organ donation. Further, as argued earlier, I found the repeated reference to some groups in interviews – religious adherents, ethnic groups and newcomers to Canada – consistent with the evidence found in public policy reports that blame is racialized.

Transplant providers, by contrast, saw TGLN as underperforming and/or blamed emergency room physicians for blocking potential donors. They also identified insufficient government funding as a problem. For example, a nephrologist told me,

It's a failure of our healthcare system and this is on the government's shoulders. People want to donate their organs, that's not the issue...what happens is that critically ill people sometimes never get to an appropriate area where they can be stabilized and their family can be approached. They die in emergency rooms and so forth (Tx2).

What needs to be prioritized is targeted financial investment with sufficient resources to identify potential deceased organ donors and initiate donor maintenance. In other words, increasing the organ supply is all about ensuring intervention to keep the organs alive so the family has the opportunity to donate. When approached appropriately, families give consent. Passionate about the issue, the same nephrologist exclaimed, "we've got to secure every donor. And hospitals need to make changes to do this" (Tx2).

While divided in pointing fingers at consent or medical intervention, both groups agreed that the people with the power to alleviate this problem are not sufficiently co-operating; more could be done. Others have given up. The same conceptualization of the problem – which ignores the donor pool – and logic of blame leads to not only to advocacy for more investment in the altruistic system but also leads to its abandonment. For example, CBC journalist Michael Enright (2011) has in recent years argued for a change the 'rigid' rule of altruism by paying live kidney donors. He cites national, comparative donors per million population figures to show that altruism is insufficient, here, and therefore no longer viable. This is complemented by the moral position of insistence that that, "we have to do something" for potential recipients (Enright, 2014). It is in these reductive ways that the problematic of shortage becomes a question of whether to commodify or not. If altruism is not working to shore up enough organs, abandoning this rule is justified.

Both promoters and critics of altruism claim that the shortage of organs causes death, even "needless" or unnecessary deaths and blame altruism as a policy line. This is evident as early as 1998, in a turning point article titled, "The Case for Allowing Kidney Sales" published in *The*

Lancet. The authors dismissed the objection of the exploitation of the poor as insufficient justification given that the, “shortage of kidneys for transplantation *causes* much suffering and death” (Radcliffe-Richards et al., 1998: 1950, emphasis added). Michelle Goodwin lays blame explicitly on altruism as a government policy. In her argument in favour of a pro-regulated market in the United States she takes the view that an organ market would be consistent with markets in other human body parts, and is necessary: “patients are shut out because too few enter altruistic procurement regimes” (Goodwin, 2013: 206). In her view,

Only those with the tenacity of athletes and the luck of lottery winners actually achieve receiving an organ in the U.S. transplant system. Others are removed from the lists, die or enter the black markets. These patients suffer needlessly under the constraints of altruism (Goodwin, 2013: 206).

Sally Satel is in agreement. She opens her book promoting donor compensation by recounting a provocative false reality television show in the Netherlands whereby viewers chose one of three people to receive a kidney from a potential donor facing a fatal diagnosis. At a news conference afterwards, the producer said, ““We have only done this cry for help because we want to solve *a problem that shouldn't be a problem*”” (Satel, 2008a: 1, emphasis added). The producers did not prescribe altruism or commodification but Satel’s (2008a: 2) interpretation is that the show demonstrated that, “the woeful lack of organs for transplantation is a problem all over the world, and the painful reality of needless death translates into all languages.” That potential recipient death can be avoided is a message shared directly with organ donor campaigns such as TGLN’s, as we saw above. Sothorn and Dickinson (2011: 890) found this claim in their analysis of a Scottish organ donation campaign, “...the message was that death is not outcome of the savage complications of organ failure but rather of our active choices as potential donors to *not* allow the use of our organs.”

The evidence presented above, showing how the dominant narrative informs two different solutions – to commodify or not – is revealing. In this light, the pro-regulated market position is less oppositional than a logical extension of recipient-centrism, even while it advocates to change a central pillar of donor protection established in *Gift Acts*. As Boas (2011: 1381) lucidly points out, “the shortage of organs supplied by public health is perceived as a failure of a policy line,” that is no longer ethically defensible given the number of people waiting and dying on transplant wait-lists. I agree with him wholeheartedly that this claim is made, “nevertheless the complex set of factors that determine the incidence of cadaveric organ donations” (Boas, 2011: 1381). Moreover, what becomes visible in the use of the discourse of donation to support abandoning altruism is what we could call, *the Zelizer route*, in reference to the claim by Viviana Zelizer (presented in chapter 2) that culture shapes money, not the reverse. It is the well-established recipient-centric discourse of donation that frames the ethical issues. This arises again in chapter 8 where we see that the terminology of “reimbursement” (instead of payment) used to describe the introduction of giving living donors money to cover the cost of the donation process.

5.8 Conclusion

By 2010, organ donor awareness and education became mandatory in high schools and all Ontarians must now be asked and respond yes/no/undecided to the question of organ donation when they renew their Ontario Health Insurance Plan card and/or driver’s licence. The same year, an electronic, advanced consent registry was launched allowing card holders to register on-line. I address how the registry is used at the time of death in chapter 6. For the argument made in this chapter, what is notable is how through aggregate statistics, the registry serves as a gauge of the level of generosity in *community altruism*. But Ontario has yet to break the 300 donors per year

goal and meeting demand remains elusive. As a senior staff member of TGLN told me, “there is a desire for a magic bullet solution. People think this should be easy” (OPO1).

The analysis made in this chapter of the development, characteristics and narrative shifts in the discourse of donation through the period of 2000-2014 demonstrates a dominant framework of understanding kidney/organ exchange that occurs through deceased donor *community altruism*. The public policy implications were demonstrated by comparing four reports over time. The size of the pool of potential deceased donors was shown to be relevant in 1985 and not in any of the public policy reports of 2000, 2007 or 2009. It was further shown that within the messages of the discourse of donation, the necessity of death, and size of the pool of potential donors are marginalized. Two standard solutions of consent, especially, but also hospital efficacy, are continually presented as the means to solve the problem of insufficient supply of organs. This focus was demonstrated to remain consistent in spite of the turn taken by transplant experts mid-decade when they expanded the pool of potential deceased donors by changing donor eligibility criteria, specifically the definition of death. Lastly, I showed how the logic of the discourse of donation is shared across altruism and the market which shows a route to introducing forms of donor payment. This chapter set the stage for my argument presented in the next chapter that the dominant knowledge obscures competing explanations for the insufficient supply of organs, alternative ways to measure success, and, how donor protection is present in deceased donation.

Chapter 6 Controversies in Deceased Donation: Seeing Donors, Protecting Donors and the Limits of Alienability

As we saw in chapter 5, the discourse of donation creates the impression that there is no tension between donors and recipients. The two parties to kidney exchange, donors and recipients, are aligned in their mutual desire to donate and in their support of altruism. Refusals to donate are implied to be unjustifiable; people make the right moral choice when educated and aware of organ donation as a desirable opportunity to help others and even an obligation of belonging to the community.

This chapter calls attention to other aspects of deceased donor *community altruism* beyond how organ exchange is presented and understood in the public realm. Here I present what I see attention being deflected from: aspects of kidney exchange for transplantation that deal with the alienability of organs from the dying. Within hospitals, in medical journals, in rare media attention moments and in policymaking the question that is debated is not how can we secure more consent to donation and improve hospital efficacy but how and when is deceased donor kidney/organ removal legitimate? This piece of the puzzle is the second half of my argument about how deceased donation *community altruism* works in Ontario during the period of 2000-2014.

There are three sites addressed in the cases presented in this chapter: Intensive Care Units and Critical Care Units (ICU/CCU) of hospitals; policymaking among intermediaries (TGLN, the Canadian Organ Replacement Register, CCDT, transplant physicians); and, to a lesser extent, the public realm. There are also two primary subjects of concern: the deceased donor as an individual, and deceased donors as a population; although, as we shall see, the object of exchange, the kidney, is the main subject. Based on my theoretical lens, I interpret the data presented below as evidence of the tension between the recipient-centrism and donor protection. This tension manifests in

several ways, all of which challenge the claims of the discourse of donation. Tension among intermediaries is also evident. Each of the cases presented in this chapter reveal organ exchange to be complex, and also suggest reasons for the disjuncture of structured forgetting. As will no doubt be evident in the issues that follow about rules of converting potential donors to actual donors and controversies regarding the pool of potential donors, my account of how organs are acquired for transplantation (presented in chapter three), is heavily informed by the evidence presented in this chapter.

The chapter is divided into three parts. In section 6.1, I examine the other side of TGLN's bureaucratic structure where staff work with hospitals to make them into sites of production. Although couched in the language of the discourse of donation, organ removal effectively constitutes these body parts as subjects. I identify how recipient-centric – donor protection tensions arise through processes of conversion within ICU/CCUs and then in proposals to push rules of conversion further by intervening earlier on donors *for* recipients. By drawing on publicly available data, I also present quantitative evidence in section 6.1.3 to support my argument that the claims of the discourse of donation are exaggerated.

In section 6.2, I examine two instances in which the pool of potential donors is 'seen' and contested. In the first instance concerning deceased donors as individuals, I show that when the legitimacy of DCD as death comes to be questioned publicly this dissent is rapidly quelled by the transplantation community. I draw on my previous research on the questioning of brain death to argue that how this controversy turns out reflects a pattern and the dominance of recipient-centrism. Questioning the shift in donor eligibility criteria is threatening because it challenges the assumption that donor protection is secure. In the second instance, I show that there is a battle between intermediaries that has yet to receive any public exposure. This is the controversy over

how to measure the pool of potential donors and know the degree to which raising the deceased donor rate is amenable to intervention. In a last section, 6.3, I deepen the understanding of what creates and contributes to the disjuncture of structured forgetting by conveying a unique case of one individual's shift from the recipient to the donor side in his approach to improving health.

6.1 TGLN's Hospital-Based Conversion Work

There is a different story to be told about what enables and inhibits kidney exchange in Ontario through deceased donor *community altruism*. As noted in previous chapters, the goal to double the deceased donor rate from 150 per year in 2000 to 300 per year by 2005 was not achieved. The highest annual rate is 247 deceased donors achieved in 2013. This has not been due to a lack of funding or effort on the part of TGLN.

Since they became operational in 2002, TGLN grew quickly to establish the staff and technical capacity to facilitate linking the ICU/CCUs of source hospitals to the seven provincial transplant centres. A Provincial Resource Centre functions as the 24-hour hub where notification of a potential donor is received; the process of donation is supported through instruction to the source hospital; the logistics of laboratory testing (to ensure the organs are healthy and determine immunological compatibility), organ recovery surgery and transport are facilitated, and finally each organ is allocated to a transplant centre for transplant surgery. Table 13 below lists eleven steps in the end-to-end process of deceased donor organ exchange.

Table 13 *The Conversion Process*

1. Potential donor identification
2. For DCD: Decision to withdraw life sustaining therapy
3. Determination of death *for NDD* (brain death)
 - Diagnosis (based on tests) and death declaration by two physicians with no relationship to the intended transplant recipients
4. Consent
5. Donor maintenance (therapy to support organs)
6. DCD: Withdrawal of life sustaining therapy
7. Determination of death *for DCD*:

- Determination of death by cardiorespiratory criteria (the absence of spontaneous respiration and the absence of a pulse pressure for a pre-determined period of time (usually 5 minutes)) by two physicians with no relationship to the intended transplant recipients. Patients must die in meeting the two criteria within 60-120 minutes for the organs to be viable.
- 8. Logistics: laboratory testing, allocation of each organ, operating rooms booked
- 9. Organ recovery surgery
- 10. Transportation of organs
- 11. Transplant surgeries

Source: TGLN Donation Resource Manual, 2010, emphasis added.

TGLN has also systematically increased its presence in neurosurgical and trauma units of hospitals (ICU/CCUs) as was called for in the Harris Report published in 2000. From a political economy perspective, TGLN's role in terms of design and degree of intervention in the ICU/CCUs of hospitals across the province amounts to instilling a new production process. From a political economy perspective, the 'making' of organs and tissues as 'medicine' can be conceptualized as a new industry and, since it is fully government funded in Ontario, an extension of the welfare state. A new object is created from the people of the province and redistributed to other people in the province. The healthcare system and medical professionals no longer just heal the ill; they also produce material—parts of human bodies for treating other patients.

6.1.1 Establishing Donation Services in ICU/CCUs

The process of implementing the donation process in the ICU/CCUs of ideally all hospitals in the province with ventilators (among 154 hospitals in the province) has involved extensive work over many years. During the five first years, the focus was on gaining legislative authority to impose regulated requirements of staff at these sites and work with individual hospitals to introduce specific policies, protocols and procedures (including reporting requirements) starting with trauma and neurosurgery units within prioritized, "Tier 1" hospitals. These hospitals – eventually 21 of them – were selected based on a Health Record Review process that identified

these institutions as high donor potential hospitals. To guide their work, TGLN joined the United States Organ Donation Breakthrough Collaborative in 2004, a consortium with the goal to “save or enhance thousands of lives by spreading ‘best practices’ to the largest hospitals to achieve organ donation rates of 75% or higher in these hospitals” (TGLN, 2006: 10). The Collaborative used various techniques borrowed from the private sector to identify what worked to increase deceased donor rates, rapidly disseminate information and monitor change through action. Through regular meetings and information systems, many of TGLN’s work processes originated with the Collaborative.

Examples of changes within hospitals include: (1) the Ministry of Health reimbursing hospitals for costs associated with *donor maintenance* (keeping the bodies of potential organ donors alive until the organs are removed)⁵⁴; (2) entering into mutual cooperation and participation agreements with an initial six, expanding to 21 *Tier 1* neurosurgical and trauma hospitals; (3) introducing Organ and Tissue Donation Coordinators at all 21 *Tier 1* hospitals; (4) establishing organ and tissue donation committees at key hospitals; and (5) training staff at other (non-*Tier 1*) hospitals as Requestors, trained to approach families for consent (TGLN, 2003). A *Routine Notification and Request* measure, recommended in the Premier Harris report of 2000, was also implemented in 2005, requiring *Tier 1* designated hospitals to notify TGLN of all deaths and for staff to routinely offer families “the option of donation as a standard part of end-of-life care” (TGLN, 2006: 8).

⁵⁴ This is called, “Continuation of therapy to support organs,” in a TGLN Donation Resource Manual (TGLN, 2010).

Thus, a structure is first put in place within the hospital to manage and ensure implementation of donation as a standard service offered by the hospital. The design is for each hospital to take ownership of their donation program through support, encouragement, empowerment and enforcement linked centrally to TGLN. The Donor Committee of the hospital ideally includes senior physicians and administrators who will champion the cause of organ donation within the hospital. The committee's work is to shepherd policy development and implementation of donation services. At the outset the donor committee is supported by TGLN to lead the adaptation of TGLN donation policies, protocols and procedures to fit the specificities of their hospital. Donation cannot happen, for example, unless ICU/CCU staff identify patients who fit eligibility criteria to be in the pool of potential donors. This is called donor identification and it is put in motion by introducing *clinical triggers* which is a set of conditions: staff must call TGLN if their patient "has sustained a severe brain injury, no neurosurgical options are available," and the patient meets all of five criteria such as ventilated, injured brain, non-recoverable injury/illness, or the family raises the topic of donation.⁵⁵ TGLN's "Donation Resource Manual," created in March 2010, integrates DCD with NDD donation processes (TGLN, 2010).

Notifying TGLN of a potential donor is not voluntary. The organ procurement organization must be notified in adherence with the *Routine Notification and Request* regulation, and a series of steps followed, including a mandated request for consent to donation. Reminders include organ donation exhortation messages such as, "Your call can create a lasting legacy by saving and enhancing lives." These measures fulfill the vision transplant physicians had in 1968 which I called

⁵⁵ My mouse pad, made by TGLN and designed for a nursing station reminds staff of the triggers. (An additional criteria that must be met is "GCS less than or equal to 4.") This reminder also states that staff must "Call TGLN for other deaths within 1 hour to ensure the ability to offer donation to eligible families." TGLN will plan for the donation discussion with families after initial eligibility has been established. www.giftoflife.on.ca

the *double gaze*: that physicians and nurses would come to view their patients not only as subjects to be healed but also as sources of *medicine* needed to treat others. TGLN facilitates the “linkages to emergency wards to constantly remind physicians of the needs of other patients,” – in other words to bring the presence of waiting potential recipients into sites where what they need to heal has the possibility of becoming available (Shapiro, 1969). Potential recipients are completely dependent upon the success of these efforts.

Ensuring that donation policies, protocols and procedures are implemented then becomes a standard and routine part of hospital work that is overseen as an ongoing responsibility of the hospital donor committee. The key staff person in charge at the front-line for ensuring donation processes are followed is the Organ and Tissue Donation Coordinator. Coordinators are paid as staff members of TGLN and are stationed within ICU/CCUs. They collect the data to regularly review the outcome of their potential donor caseload with the donation committee. Together they identify ways to improve practice, including committee members influencing any senior staff in the ICU/CCU who is resisting compliance and dismissing the authority of the nurse Co-ordinator in ensuring donation procedures are followed. (I was also told by the Organ Donation Co-ordinator I interviewed that if nursing staff do not follow donation policies, she reports this misstep to the nurses’ manager for disciplinary action (OPO 4)).

Organ Donation Co-ordinators are continuously trained by TGLN on effective request-for-consent techniques and are supported continuously by the TGLN central office. They participate in daily teleconference calls with their counterparts at hospitals to support one-another through case reviews. The Co-ordinator job is nevertheless well-known to be stressful and have a high-turnover.

In 2007-2008 the approach to consent changed. In a National Consent Training Workshop TGLN hosted with the Philadelphia Gift of Life Institute and the CCDT, participants learned about a new innovation in the field of organ donation called the value-positive approach to obtaining consent. It was developed by the Philadelphia Institute and adopted by TGLN in 2006. A senior staff member at TGLN explained to me that they used to approach the family tentatively and start with an explanation of brain death (OPO 3). Further, some families were not approached because it was assumed that they might be offended on religious or cultural grounds. By contrast, the value-positive approach “decouples” death from donation and assumes the desire to give (TGLN, 2010: 29). There are two facets of this approach that are new. One is that coordinators are trained to be positive in tone and language. This is based on research showing that “families are more likely to donate if the requesting person has a positive attitude about donation” (TGLN, 2010: 31). Also, coordinators speak to the family twice: once to inform them that their loved has died, including providing a time of death; and, later – only once the family has accepted the fact of death – is a separate conversation about the opportunity for donation held. The approach, “is built on the belief that most people, given the opportunity to save lives and help others, will choose to do so” (TGLN, 2008b: 13). Analytically, this approach to consent creates a division between alienability and altruism which is consistent with the approach to advanced consent. As a result, whether one is able to give is conceptually separated from the question of whether one wants and agrees to give.

The goal is to take every action possible not to miss a single potential donor. As part of their positive approach, TGLN cultivates and rewards individual donor champions and hospital champions in annual province-wide award ceremonies. The sense of a moral cause is present in TGLN’s work with hospitals in the same way as their media campaigns: through the discourse of donation. However, some variables are not fully in the hands of interveners. As we saw above,

DCD donors must die in within a set time-period or the organs will not be viable and donors must be free of counter-indications to donation. Consent is an aspect of system performance but even asking “the right way” will not convince everyone. I asked a senior staff member of TGLN whether this work is frustrating. The interviewee chuckled but agreed, saying, “the co-ordinator can do everything perfectly and the answer can still be “no” (OPO 1). As verified in the data below, approximately one of every four requests for consent at the bedside are given the answer, ‘no’. On the one hand, this dumbfounded the TGLN staff. However, on two occasions, there was an acknowledgement of ‘no’s that were well-founded, these were called, ‘the good ‘no’s’. In one instance, the story was that the family stood bedside for a week only to see their child die instead of recover. Since donation requires the family to wait an additional twenty-four hours as the organs are recovered in the operating room, this delays closure. I was told that, “they just couldn’t do it” (OPO 1). Inalienability, not lack of generosity, was the barrier to donation in this case.

The two central challenges confronting TGLN at the time of my interviews in 2010 remained the two aspects of instilling the culture of donation. First, among the public, to persuade people to consent to donation, and, second, in ICU/CCUs where intensivists (the physicians in these units) were accused of blocking donation processes. One important change accomplished in 2010 was the introduction of an electronic registry of advanced consent to organ donation, within the Ontario Health Insurance Plan database. This registry replaces consent on organ donor cards. As mentioned in chapter 5, this development was recommended in the 2007 Citizens Panel report. I learned in my interviews that it is what is called an “affirmative” registry as only ‘yes’ answers are collected. Given their mandate, TGLN staff told me, “We don’t want to know, ‘no’. We are better off not knowing ‘no’ because then we can still approach the family for consent” (OPO 2). With public notice, previously recorded refusals to consent were dropped from the system. TGLN’s Donation

Resource Manual guides staff to actualize precisely the individual rights approach taken in the Citizens Panel report. Although family veto remains the practice in Ontario, throughout the manual, staff are instructed to call TGLN early in order for a registry search to be conducted. If found,

The TGLN coordinator will provide the consent information to the donor's family members at the appropriate time. TGLN works closely with the healthcare team to honour the person's choice to donate. Ongoing support is provided to the patient's family to help them understand the donation process and the meaningful decision their loved one has made to save and enhance lives (TGLN, 2010: 29).

The affirmative consent registry serves as means to convince families to consent to donation by showing them proof of individual consent. As a result, the relationship of facilitating exchange is made directly, from the individual to the state, with the family side-stepped, at least in principle. Also notable is the absence of the potential recipient in this narrative of giving which is claimed to be by and for the donor. The creation of the registry is pursued based on evidence of effectiveness. "Although 79% of Ontarians state they would donate an organ for transplantation at death, the consent rate for organ donation is only 55%" (TGLN, 2010). I was told in my interviews that 80% of families agree when shown proof of donation registration (OPO 2).

6.1.2 Measurement

In the face of the challenge made by Premier Harris to double the donor rate within only a few years, TGLN prioritized establishing an alternative performance measure, the politics of which are addressed below in section 6.2.2b. The organization's first annual report, of 2002–2003, described initial work on an organ donation scorecard:

This scorecard introduces a new and more meaningful way of monitoring organ donation activity, with a view to determining the potential for organ donation in a geographic area, and the factors that influence actual donations.

The present unofficial practice of measuring cadaveric organ donation performance by dividing the number of donors in a jurisdiction into the overall population in that area and expressing this as “donors per million of population” (dpmp) *is increasingly considered to be an inaccurate measurement of organ donation performance*. It does not take into account that as a result of such things as motorcycle helmet and seatbelt laws or the frequency of gunshot deaths, the number of brain dead persons, and accordingly the number of potential organ donors, may vary from jurisdiction to jurisdiction (TGLN, 2003: 10, emphasis added).

Subsequent annual reports show the evolution of establishing data collection and a means to calculate a *conversion rate* measure of organ donation, modeled after the American Breakthrough Collaborative methodology.

The general conversion rate is determined by dividing the number of actual deceased donors by the number of potential deceased donors. TGLN interviewees identified that the “weak spot” in the conversion rate is a data collection and definitional problem. When retrospective chart reviews are relied upon to establish the number of potential donors, poor reporting of patient conditions weaken the reliability of the data.

A more nuanced conversion rate accounts for different steps in the donation process in-between potential donor identification and actual donation. The more nuanced analysis is more labour intensive and is therefore for “Tier 1,” prioritized hospitals only. Based on data from the routine notification and request rule—according to which designated hospitals must report all intensive and critical care deaths and potential donors—TGLN can calculate the more nuanced conversion rate. This was reported to be accomplished in the 2006–2007 annual report. Isolated within the calculation are four necessary steps to the donation process, moving from potential eligible cases to actual donors (what I call aspects of conversion in chapter 3): (1) a referral rate;

(2) a declaration of death rate; (3) an approach for consent rate; (4) a consent rate; and (5) a recovery of organs rate. This level of data collection enables TGLN to identify the success of what they can do to increase the volume of organs, which is to try to gain consent from the family and for hospital processes to be efficacious – the two standard solutions, – measured as a percentage of the potential donor pool.

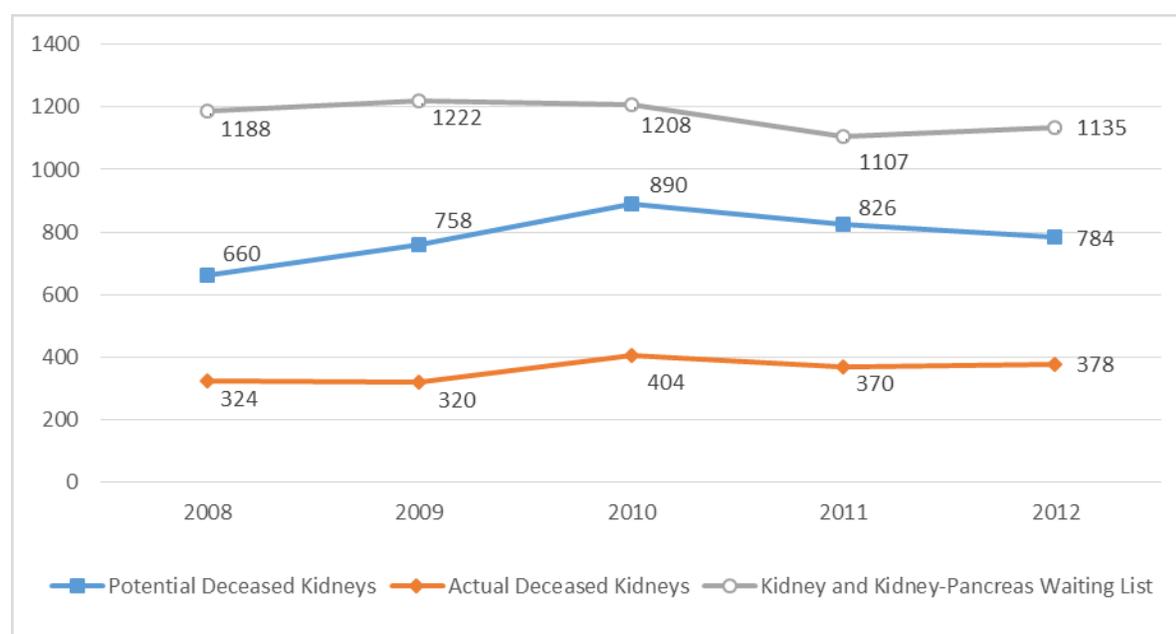
Thus, over the fourteen year period under study, TGLNs annual reports show the financial investment of specific funding to cover the cost of *donor maintenance* and the outputs from hospitals of donor counts, and potential donor to actual donor conversion rates. Organ utilization rates and transplant rates are published with an increasing level of detail and breadth in the data offered each year. In the annual report of 2006-2007, deceased donor organ imports and exports to and from other jurisdictions begin to be reported, just like a new commodity market. The same year, the number of deceased donors for the year at designated hospitals is reported, along with the annual funding given to these institutions to cover the cost of donor maintenance. Finally, in 2011-2012 hospital-level conversion rate data are included in the annual report for 21 “Tier 1” hospitals showing figures over a three year span. This allows hospital performance to be directly and publicly compared.

6.1.3 Profile

What does the profile of Ontario’s deceased donor *community altruism* look like based on the data generated by TGLN? And how does this compare to the picture painted in TGLN media campaigns? Readers will recall that in chapter 5, the 2009 Wait Times report emphasized DPMP evidence, for example, stating that “in 2008, the US rate was 27.8 PMP compared to 14.1 PMP in Ontario” (Ontario, 2009: 11). Why did this report not use TGLN data in their analysis? Although

it is clear that demand is unmet, the data presented below in Figure 1 and Table 1 present a far more nuanced picture than is included in the public policy reports of 2000, 2007 and 2009. Note that Figure 1 data only include 21 hospitals and counts of not donors but kidneys (numbers are therefore twice the number of donors based on the assumption of two kidneys recovered from each deceased donor).⁵⁶

Figure 4 *Estimated Actual and Potential Deceased Donor Kidneys Compared to Kidney Waiting List, 2008-2012*



Source: TGLN annual reports, covering the period of 2008-2012

Notes:

1. Most recent figures used based on a fiscal year from April 1 of the previous year to March 31 of the year reported. Data are from 21 Tier 1 Hospitals; Includes NDD (brain death) and DCD (Donation after Cardiocirculatory Death).
2. The waiting list figures combine the lists for kidneys and kidney-pancreases.
3. All numbers are accurate, the estimation comes from an assumption of 2 kidneys donated from every kidney donor. Thus, Potential and Actual Deceased Kidney figures were calculated using Organ Donor numbers multiplied by two.
4. Potential donors include all cases from three categories:
 - a. Cases with at least one documented declaration of brain death and free of exclusionary medical conditions
 - b. Cases with documented clinical findings consistent with but not declared as brain death, also free of exclusionary medical conditions; and

⁵⁶ Note that I found minor discrepancies in numbers between different sources: the TGLN TOTAL database, TGLN annual reports and Ontario public policy reports.

c. Realized DCD (Donation after Cardiac Death) cases

Based on publicly available “Highlights” from annual reports not yet released, the actual number of donors for 2013 reaches a peak for the 2000-2014 time period at 247 for an estimated 494 kidneys with a conversion rate that is also the highest on record at 63 percent. But data for the 2013-2014 fiscal year show a drop to 223 deceased donors with a 52 percent conversion rate.

What Figure 4 illustrates is that even if every potential donor became an actual donor resulting in a 100 percent conversion rate, the number of kidneys from deceased donors is still insufficient to meet demand. There is a shortfall between the waitlist and the potential number of kidneys from deceased donors that ranges from a high of 528 kidneys in 2008 to a low of 281 kidneys in 2011. The average over five years is a shortfall of 388.4 kidneys. This finding substantiates for Ontario what Sheehy and colleagues (below) found in the United States in 2003. Also, the slight fluctuations of each line conveys that the number of patients waiting for a deceased donor is declining and more potential donors are being identified. There are a number of possible explanations for each of these trends. Last, what is also apparent in Figure 1 is that only half of all deceased donors become actual donors. Table 14, below, provides a closer look at the break down of the variables that constitute the conversion rate to inform an analysis of why the conversion rate is not higher.

Table 14 TGLN Deceased Donor Conversion Rate, 21 Tier 1 Hospitals, 2008-2012

	2008	2009	2010	2011	2012	Average over 5 Years
Potential Organ Donors	330	379	445	413	392	381
Actual Organ Donors	162	160	202	185	189	191.8
Referral Rate %	94	96	97	98	98	96.6
Declaration Rate %	75	72	69	68	73	71.4
Approach Rate %	86	83	83	80	88	84
Consent Rate %	61	66	69	74	73	68.6
Recovery Rate %	87	85	86	89	85	86.4

Conversion Rate %	49	49	53	55	60	53.2
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Source: TGLN annual reports, covering the period of 2008-2012. Tier 1 Hospitals = 21. This is the most recent data available.

The variable that is the lowest in this tabulation is consent. Although consent to donation rises by over ten percentage points over the five year period (from 61 to 73 percent), it stands at 68.6 percent as an average over the five year period. Consent has improved from losing 1 in every 4 potential donors to close to 1 in every 3 potential donors. But why are there any refusals to consent to deceased organ donation? The next lowest variable is the declaration of death rate at an average of 71.4 percent. Does the type of death – NDD or DCD – matter to this step in the donation process? Does this reflect an issue regarding the patient meeting the diagnosis or a logistical barrier related to the requirement that two independent physicians issue the death declaration?

These data indicate that there is room for conversion work to increase the number of actual deceased organ donors, assuming that more people can be convinced to donate and that the reason for a 71.4 percent donor declaration rate is resolvable. This means that the two standard solutions proposed through the discourse of donation of consent and hospital efficacy do matter. But the constraint on the two variables remains the size of the pool of potential deceased donors. There is a limit. Unlike the messages of the discourse of donation, consent and hospital efficacy alone cannot increase the number of organs.

A major thrust of the 2009 Wait Times report (reviewed in chapter 5) was identifying policy mechanisms to ensure hospital compliance in implementing the donation process. This report partially critiqued TGLN's effort to that end, and, helped give this work external endorsement. It also reflects the leadership of this report by transplant physicians who are dependent upon 'source' ICU/CCUs for organs. In my interviews in 2010, one effort was to tie organ donation performance

results – meaning donor numbers or conversion rates – to hospital accreditation. In the TGLN 2011-2012 annual report, another approach is taken which is to publish hospital level results, starting with the 21 Tier 1 hospitals. The table in the appendix listing hospitals reveals a very wide range conversion rates at the hospital level, from the Grand River Hospital Corporation at 22% to St. Mary's General Hospital at 100%, both located in the South West region. The effect of strategies such as accreditation and public exposure, as well as other approaches aimed at enabling donation require further research. The dynamics of the social relationship between these intermediaries – from TGLN to 'source' hospitals – signal that these mezzo-level exchanges are political.

Part of what is striking about the implementation of organ acquisition efforts in more and more hospitals is the disconnection between this work and TGLN's public focus on consent. But this is not a conflict from the organization's point-of-view. TGLN is simply meeting its mandate to create a supply of organs and tissues by working in tandem on different aspects of the conversion process using the techniques deemed 'best practices' for each. How consent is acquired and how the donation process is instilled are separate matters. The organization must convince people to donate and therefore public campaign messages convey messages deemed persuasive. Sharing the details – considered technical – about the donation process as it is experienced by ICU/CCU staff is not necessary or persuasive.

Each annual report produced by TGLN concludes with praise and a call to work harder,

Overall, we look back on 2006/07 as a year in which a great deal was accomplished. There were more organ and tissue donations than ever before resulting in more lives being saved. That being said 1748 people are still on the waiting list for organ transplants. The fact that every three days someone dies waiting for a transplant is all the incentive we at TGLN could ever need to redouble our efforts in the year to come (Ontario, 2007: 7).

But the data above suggest that a more frank summary that would avoid unrealistic expectations would be: “It is impossible to meet the need for organs because there are not enough potential organ donors relative to potential recipients on the waiting list. This means that some of the 1748 people still on the waiting list for organ transplants will die and others will continue to rely on dialysis. What we can do is keep trying to improve the conversion rate until we reach a level of 100 percent effectiveness which will save twice as many lives.”

Table 15 below contrasts the different ways of measuring the deceased donor rate using the donor rate per million population as is used by the Canadian Organ Replacement Register (CORR), compared to TGLN’s conversion rate (which is available in their annual report but is not publicized). I add calculations of the shortfall in the number of kidneys from deceased donors (based on Figure 1 and Table 1, above). What we see is that during this five-year time period, if the conversion rate was 100 percent (instead of 53.2 percent), 424.4 more ESRD patients on the wait list for a deceased donor kidney would have received a kidney. The unfortunate reality is that receiving a kidney is impossible for 388 of the same pool of transplant candidates due to the limitation of the size of the potential deceased donor pool. As we saw in chapter 5, public policy over the period of 2000-2014 was based on a presumption regarding the size of the pool of potential donors. Baxter’s calculations actually measuring the pool were ignored. Now the data are available to show that in the fact that Ontario’s system is slightly more than half effective over this time period. Here I analyze the data and raise questions about data usage by different parties. In section 6.2.2, below, I show how the deceased donor measure is contested.

Table 15 Comparison of Deceased Donor Rate Measures and Estimated Kidney Shortfall, Ontario, 2008-2012

		2008	2009	2010	2011	2012	Average
CORR (All Hosps)	DPMP	13.6	16.7	15.1	16.3	18.7	16.08
	Conversion Rate	49%	49%	53%	55%	60%	53.2%
TGLN (21 Tier 1 Hospitals)	Actual Deceased Donors	162	160	202	185	189	191.8
	From Figure 4:						
	• Estimated Kidney Shortfall that cannot be met (Waiting List – Potential Donors)	528	464	318	281	351	388
	• Estimated Kidney Shortfall that can be met (Potential – Actual Donors)	336	438	486	456	406	424.4

Sources: Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2003-2012 (CORR, 2014a). TGLN annual reports, covering the period of 2005-2012.

What we also see in Table 15 is how the conversion rate appears relative to the deceased donors per million (DPMP) rate. Although as a percentage, the conversion rate is easier to grasp, neither have great meaning without comparison. We saw several times earlier that Canada's DPMP is commonly compared to the United States and Spain. In 2000, Premier Harris used Ontario's annual deceased organ donor rate at 14.1 donors per million population (DPMP) compared to 33.8 in Pennsylvania and 33.6 in Spain to claim Ontario has a crisis (Boyle, 2000; Ontario, 2000). In 2014, on September 27, the current federal Minister of Health, the Honourable Rona Ambrose's announcement for an Organ and Tissue Donor Social Media Campaign included a poster comparing donors per million population for Canada at 15.6, the U.S.A. at 25.8 and Spain at 36.1 with the message "we can do better" (see Appendix 2)(Health Canada, 2014). Donors per million population, compared in the standard way, makes Ontario and Canada look like severe underachievers that have not made any progress when much greater heights are entirely possible. Jurisdictional conversion rates have yet to be compared publicly or in policy reports.

Another perspective on where Ontario stands, over time and in relation to other jurisdictions, is now possible using the limited deceased donor conversion rate data that is

available.⁵⁷ In 2000 demographer David Baxter (2000b) determined that Ontario had a rate of 43.2 donors per 1000 eligible deaths, which was above the national average. This put Ontario in a positive light as a reasonably successful jurisdiction at that time, and at 53.2 percent in 2010 (in Table 15) indicates a decade of improvement. But conversion rates are higher in the United States. In 2012, the conversion rate in the United States was 72.5 eligible donors per 100 eligible deaths (OPTN/SRTR, 2012). The range from six Donor Service Areas is from 64.69 at the low end to 83.62 at the high end, and for kidneys, the national donation/conversion rate was 67 (1 or 2 kidneys recovered) eligible donors per 100 eligible deaths. Assuming the definition for each variable is the same, the Baxter and American data are informative.⁵⁸ It tells us that Ontario's rate did improve over the time period but that the province currently has a lower organ donor rate than elsewhere.

What discerning the variables also points out is the need for caution in attributing causality, and the significance of dependence on mortality. In taking into account the pool of potential donors, the conversion rate is independent of the number of deceased donors. It is a performance measure that is considered fairer because TGLN only has a given population to work with in trying to convert potential donors to actual donors. But we do not move away from dependence on mortality. This means that if the pool decreases in size, so do the number of organs, even in a perfect system with a 100% conversion rate. And, the inverse is also true. Figure 1, above, and evidence presented in chapter 4 show that the increases in actual donors follows the increase in potential donors which is attributed to expanding the donor pool by introducing DCD. This poses the question of how much we should be investing in the system if the desired outcome is more

⁵⁷ I could not find conversion rate data for other jurisdictions in Canada based on a standard search of OPO websites.

⁵⁸ There is a debate over who to include in the potential donor category and what data to rely upon in collecting this data. Data issues of this nature formed the subject of a Canadian Organ Replacement Register report in 2001 and CCDT work on this topic; both efforts are addressed below in section 6.2.2b.

dependent upon the pool – constituted by donor eligibility criteria, and for deceased donation by mortality. Deceased donor eligibility criteria, while they are (as I argued in chapter 3) ‘rules of alienability’ that are developed in the abstract, they are not theoretical. The TGLN Donor Resource Manual (used as evidence, above) demonstrates that criteria are enacted in practice through the mechanism of *clinical triggers* as a general process that my interviewees referred to as, “seeing potential” (OPO 4). Mortality, on the other hand, needs to be monitored and included in how transplantation and the system of deceased donation is understood. As we see below (in section 6.2.2), in the work of Dr. Christopher Doig and colleagues, epidemiological research on deceased donor mortality has resumed in Canada (not addressed since Baxter’s work in 2000), and was inspired by the introduction of DCD.

The conversion data used in Table 1 is publicly available in TGLN’s annual reports which are posted on their website. Yet, these data are not used, even within academia. A recent article, by John S. Gill, Scott Klarenbach, Lianne Barnieh, Timothy Caulfield, Greg Knoll, Adeera Levin and Edward H. Cole (2014), ignores TGLN conversion data in making an argument in favour of introducing monetary incentives in Canada. Instead, the authors claim that, “unlike the United States, the potential to increase organ donation in Canada may be sufficient to meet the need for transplantation,” and, further, that their own unpublished study suggests “significant potential to increase the number of deceased donors” (J. S. Gill et al., 2014: 133). The question is why is the conversion rate not used to inform what is known about deceased donor *community altruism* in the public realm, in scholarship that seeks to influence public policy, and in public policy itself? My answer, argued below (in section 6.2.2), is that measuring deceased donors is political.

Based on the data presented in this section, Ontario’s deceased donor system is efficacious. Further, my calculations, above, also demonstrate that Ontario can do better, but the impression

created that the province can do far better and save everyone – that this is “a problem that shouldn’t be a problem” – is false; it denies the limitation imposed by the size of the deceased donor pool (Satel, 2008a: 1). In other words, it belies organ origins and thus constitutes the disjuncture of *structured forgetting*. The quantitative findings, above, demonstrate that the reason for the organ shortage is both the size of the pool of potential donors, and the system; not just the system. Thus, justifications for changing the system – by abandoning or weakening the non-remuneration clause of altruism – based solely on blaming the altruistic system for the organ shortage are unfounded. The intention of people who want to improve the deceased donor system is noble and the cause is moral. However, the claims of academics and government messages to the public exaggerate the number of deceased donor organs that can possibly be acquired. As a consequence, other values – of honesty, accountability and transparency – are compromised with the worst possible effect of making people angry (as we saw in chapter 5) and raising false hope among potential recipients.

6.1.4 The Search for ‘Ethical’ Openings and Resistance to ‘Unethical’ Boundary

Pushing

I found in my research that, the regular surfacing of the, “to commodify or not,” question in organ donation deflects attention from an actual *line in the sand* regarding alienability. With respect to deceased donation, given that dying is a process of organic decline, the rules of alienability are not just categorical but temporal. This was evident earlier, in chapter 3, in the quote by former Member of Parliament, Keith Martin who asked whether it was fair for a potential recipient to have to wait for the donor to “so-called die” before the organs are removed (Canada, 1999c). As we saw, above, *donor maintenance* refers to the medical work that must always occur: the flow of blood must continue to keep organs alive in the dying body until each one is extracted

in sequential donative surgeries for transplantation. The question is *when* to initiate this work. The recipient-centric – donor-protection tension is heightened in donor maintenance since early intervention preserves organ quality as the body/person dies and delayed intervention degrades organ quality. This is one of many contested lines where boundary pushing and resistance occurs. A senior staff member raised this topic in response to my question, ‘how can the organ shortage be resolved.’ The interviewee informed me that there is potential on this point to increase the number of deceased donors but that this possibility “raises ethical questions. Is it right to insert a medical device and/or administer drugs *that are not to the benefit of the potential donor prior to death declaration?*” (OPO 1).

Later in my research, I found that the TGLN Donation Resource Manual deals with the ‘when’ question by making intervention *for recipients* permissible. The manual describes that families sign an initial *Consent to Donate* form, and, for DCD, a second form titled, *Consent for Pre-mortem Treatment*. The latter,

...is also required as optimal protocol includes pre-mortem interventions to facilitate the best possible outcome for recovered organs/tissues. These interventions pose *minimal risk* to the patient, and will not be used or continue if there is any indication that death will be hastened as a result. The following are considered interventions that may be performed:

- A trial period off the ventilator which predicts the timing of deterioration of patient vital signs after withdrawal of life sustaining therapy.
- Testing and/or procedures similar to those performed in the case of NDD, e.g. serology for infectious diseases, blood type, as well as organs-specific testing and evaluation such as CXR or bronchoscopy.
- Medical management to stabilize the donor.
- Anticoagulants administered prior to death while the heart continues to beat to avoid clotting and ensure circulation and perfusion to all organs.

Some hospital policies may also include femoral cannulation in anticipation of upcoming recovery in the operating room (TGLN, 2010: 32, emphasis added).⁵⁹

⁵⁹ Femoral cannulation is the insertion of a cannula (which is a tube to deliver or remove fluid or for gathering data) in the femoral artery, which is a large artery in the thigh.

This consent form identifies the organs/tissues as the subjects – patients – of medical intervention. And in identifying risk to the patient, there is an acknowledgement of conflict between the best interests of the donor and the recipient in the donation process. It is in these moments that living donation experts acknowledge that ethical principles of determining a balance between beneficence and non-maleficence are invoked, and, as we see in chapter 8, where to draw that line is not always clear. Why is such an acknowledgement not raised here? As we see later in this chapter, the donation process overall does invoke contestation.

A similar but public ethical debate asked whether it is right to use specialized ambulances to initiate *donor maintenance* on potential donors prior to patients reaching the hospital. In a few jurisdictions in the United States, and recently in Manitoba, a second ambulance is sent out to physiologically maintain the organs of a potential donor who is declared dead in a first ambulance (OPO1). Such a tactic is seen to address the challenge that the vast majority of sudden deaths occur outside of hospitals; enabling emergency medical staff to perform *early donor maintenance* is designed, then, to secure more donors.

When a second ambulance pilot project was initiated in New York City, the medical officer for the coroner's office objected (Hartocollis, 2010). Not only are the interests of the donor and recipient potentially at odds, but as Timmermans (2002) found, the encroachment of OPOs on the territory of crime investigators creates a conflict between different branches of government and public goods. The question in this regard is whether the public is better served solving (and thus potentially preventing) crime versus saving the lives of transplant candidates. In the case Timmermans studied, organ donation was poised to morally trump criminal investigation. To avoid this type of jurisdictional conflict of interest, I was told by TGLN senior staff that only stroke

victims (not violent crime victims) whose next-of-kin are present and consent would be candidates for *early donor maintenance* in second ambulances (OPO1). However, in 2010, Ontario was not yet considering this option.

In another example provided to me in interviews with TGLN, I was told that few people are aware that aspects of Spain’s much heralded organ donation system “raise ethical flags” that may not be considered acceptable in Ontario (OPO 1). An underpublicized aspect of Spain’s reported success in achieving high rates of organ donation is the fact that organ procurement organization representatives in intensive and critical care units are compensated at least partially on commission—more donors means more personal financial reward. Less frequently, burial expenses are also covered for some donors. When debate over money arises the only consideration is, indeed, the question of individual/family remuneration to increase motivation to consent to donation. This example notably identifies other aspects of financial reward for intermediaries that could be introduced to increase co-operation with the donation process.

As noted, pre-mortem intervention and incentivizing organ recovery in many ways match what we see later, in chapters 7 and especially 8, where rules of alienability for living donation are more openly contested. There is a parallel between deceased and living donation that captures the doubt and drive involved which is to consider these cases as forms of searching for ethical openings to expand the donor pool without infringing on donors such that organs are not valued ahead of persons.

6.2 Seeing the Recipient-centric – Donor protection Tension

This section analyzes two instances of contestation that arise from the assertion of a deceased donor viewpoint. In the first, the discourse of donation is publicly breached by challenges to “the

dead donor rule.” Instead of taking for granted the new DCD diagnosis, a small set of dissenters challenge the legitimacy of deceased donation established by the authenticity of the diagnosis of death. This challenge provokes rebuke by transplant intermediaries. Second, is the disagreement described in chapter 1 and traced over time in the previous chapter regarding how to measure the donor rate: based on live population using a donors per million population measure, or, trying to measure the size of the pool of potential donors. I argue that both cases reveal the tension between recipient-centrism and donor protection that the discourse of donation renders invisible.

6.2.1 Breach

In keeping with my theoretical account of transplantation in chapter 3, gaining access to the dying requires, first and foremost, predominance of the medical profession over death such that declaration of death is accepted based on medical evidence. Removing organs further requires the authority to intervene in the process of dying, and the ability to do so at the right moment. Some scholars have emphasized the crucial role the ventilator has played in this possibility (Sharp, 2007). Without this machine, dying proceeds.

In my earlier research, I argued that,

...the classification ‘brain death’ semantically and in practice bridges two understandings of the end of personhood: as an event and as a process. By qualifying part of the body as dead, a process of disintegration is implied while the term ‘dead’ signifies a moment of time at which life is over. If the same state was called ‘body alive’, it would imply the inverse: that a person is still present (McKay, 2001: 62)

Thus, the creation of the concept, through the diagnosis of ‘brain death,’ is a “temporary expression of knowledge/power” in the way Michel Foucault (1980) conceived of such forms of power. I also argued that, “the purpose of the classification ‘brain dead’ is to mark a point at which

the patient is alive enough to be useful but dead enough to use” and that “the critical division made by application of the diagnosis is the absence of personhood” (McKay, 2001: 62). This was consistent with Lock’s (1996c) analysis that the significance of the judgement, based on the brain, is to say that “meaningful life” is over. Dying patients are ‘bioavailable’ because they are no longer persons. My earlier research demonstrated that brain death came to be accepted in Canada as a firm ‘truth’ based on scientific legitimacy and a ‘discourse of donation’ form of justification.

As raised throughout the thesis, ‘DCD’ for ‘Donation after Cardiocirculatory Death’ introduced new criteria for death based on the cessation of the heart rather than the brain (or, as TGLN and others assert, *re*introduced new criteria by reverting to criteria used prior to a diagnosis for brain death). Regardless of interpretation, DCD is recorded in statistical collection as distinct and even if only on this basis amounts to a second type of death coming into practice in Ontario in 2006. The process followed to create this new diagnosis has been described. And, its impact in raising the number of deceased donors was noted in chapter 4. Here I turn to a point mentioned in the introduction, that DCD has not been accepted everywhere in Canada. Having studied a challenge and dismissal to the claim that “brain death is death,” at a public hearing in 1999 in my Master’s thesis (described earlier), I show in this section how history has come to repeat itself.

In 2006, 2010 and 2013, articles appeared in Canadian and non-Canadian medical journals by a small group of physicians articulating an objection to the endorsement of DCD by transplant intermediaries and the majority of experts. In 2010 this controversy was reported in the media. It provoked the same kind of refutation to the questioning of death that transpired in 1999 (see McKay, 2001). In response to negative media regarding DCD, a joint press release was distributed to the media by TGLN, its British Columbia and Quebec OPO counterparts and the new, national intermediary, Canadian Blood Services. It read:

Recent media coverage about donation after cardiac dead (DCD) may have left some Canadians with the false impression that donation and transplantation procedures occur before a donor has actually died, and that family members are being misled into thinking otherwise. This is simply not true (Canadian Blood Services, BC Transplant, Trillium Gift of Life Network, & Québec Transplant, 2010).

The interests of potential recipients, actual recipients and these organizational intermediaries were at stake. Their answer was to assert a truth. This repeated what I found in 1999, that the ability to stand on a well-formed social consensus legitimated experts' refutation.

In 2014, at the time of writing, the debate occurring in medical journals was again exposed to the public but this time in a television documentary called "Dead Enough" by CBC's television program, *The Fifth Estate*, which was broadcast on March 21. The lead synopsis of the episode was that,

The standards for defining death in Canada vary so much that the hospital where a dying person ends up may affect when they are declared dead – and that has some Canadian doctors concerned about the implications for organ donation (CBC, 2014).

The tagline was that the definition of death was not universal. The CCDT national guidelines recommend physicians wait at least five minutes after the heart stops beating but policies are hospital and or jurisdiction specific.⁶⁰ A person is declared dead at Toronto's Sunnybrook Hospital and the Toronto General Hospital after a five minute wait, but the wait is ten minutes at Toronto's St. Michael's Hospital in Toronto. "In Pittsburgh, Pennsylvania, it is two minutes, while in Denver, Colorado, the wait is just 75 seconds. In Italy, it takes longer – doctors must wait a minimum of 20 minutes after the heart stops to declare death" (CBC, 2014). This is described by

⁶⁰ Differences in specific DCD policies substantiates findings from my research on living donor evaluation, presented in chapter 8, that the relative autonomy to follow local policy locates power at the level of the hospital and transplant centre.

lawyer Jacquelyn Shaw in the documentary as “postal code death” (CBC, 2014) (Shaw, 2012). My research found, however, that it is also religion that informs the different waiting periods. In Toronto, at least, death at a Catholic hospital requires an extra 5 minutes.

The CBC show included two cases of death diagnosis recovery: Shane Becker at the Vancouver General Hospital in 2006, and the interviewed but unnamed daughter of Sharon Thompson at a Calgary hospital (with no year provided). Both Shane and the unnamed daughter are claimed to have met the criteria for death diagnosis yet they each recovered prior to organ removal. Becker’s mother had already consented to donation; Thompson felt under pressure to consent. CBC used dramatic music in the documentary and claimed that the question of when you are dead remains, “remarkably unresolved” (CBC, 2014).

Key interviews are conducted in the hour length documentary with experts who express different grounds for objecting to the new diagnosis. One expert is a lawyer and health law expert, Jacquelyn Shaw, who published an article on this issue in the *McGill Journal of Law and Health* in 2012. She is presented criticizing the process of authenticating DCD for not consulting the public, and suggesting that the lack of public engagement contributes to refusals to consent. Shaw’s article (2012) asserts that, “aspects of this redefinition raise patient safety concerns because they reveal a potential for physicians to declare death significantly earlier, and with greater chance of error, than previous brain death guidelines.” She writes of a concern that the CCDT guidelines for DCD may infringe sections of the Canadian constitution, specifically *Charter of Rights and Freedoms* sections regarding rights to life and security of the person and of fundamental justice.

Another expert interviewed in the CBC documentary, Dr. Ari Joffe, a pediatrician in the ICU at the Stollery Children’s Hospital in Edmonton, argued that the evidence to support DCD as

a diagnosis of death is not incontrovertible. Joffe's view is one of several dissenting voices. Although not in the CBC documentary, a well-known critic of DCD is Dr. Christopher Doig, who was one of two physicians to initiate the CCDDT sponsored process of considering DCD in 2005 (the process is described in chapter 5, section 5.3). Doig (2006) did not become a signatory to the DCD guidelines, instead articulating his dissenting view in an article titled, *Is the Canadian health care system ready for donation after cardiac death? A note of caution*. One of my key informants told me that what dissenters to DCD disagree with, "is that DCD leads to brain death" (Tx 3).

The parallels to the dissent by three physicians at the House of Commons hearing in 1999 are striking. Medical evidence also served as the grounds for dissent from the validity of brain death diagnosis by two of the three physicians. Moreover, transplantation intermediaries responded in the same fashion: by discrediting dissenters. This time, in 2014, intensivists, the physicians who care for potential donors, were in agreement. Among twenty-one comments posted on-line was a submission by The Canadian Critical Care Society. On behalf of the Society, its chair, raised several points of concern with the CBC documentary. Most notable to this analysis is the following:

We are concerned that families who have generously given consent for organ donation at the time of a significant loss may be harmed by doubts that your show could have created... We hope that the inaccuracies in your story do not detract from this act of altruism (CBC, 2014).

In this assertion, not only are dissenting views claimed to be inaccurate, they provoke fear of harm. The very possibility of public deliberation of the criteria that establish death – in other words the legitimacy of alienability – are viewed as harmful (implying offensive) to donor families, and harmful to persuading future potential donors to consent.

Along these lines, three physicians who disagree with the contemporary criteria for death, Mohamed Y. Rady, Joan L. McGregor and Joseph L. Verheijde (2012), published a research article that strongly criticized mass media campaigns about organ donation for failing to disclose controversial aspects of organ donation. Calling campaigns, “propaganda,” the authors argued that organ donor campaigns were biased, provided misinformation, and that there was an unmanaged conflict of interest between recipients and donors (Rady et al., 2012). Scholars of such campaigns, Morgan and Freeley (2013: 865) replied with a “clarification,” arguing that the trio make false claims, and defer the issue of death to “leading neurologists.” The pair then direct readers towards their focus which is the role of campaigns in countering misleading ideas about donation and transplantation in the mass media. Rady, McGregor and Verheijde (2013: 870) replied, in a third article in this exchange, arguing that, “campaign designers should disclose the persisting controversy over the concept of brain death when developing media campaign strategies to promote organ donation.” Taking an even more entrenched position, the trio argued that the disclosure they advocate for reflect the ethical dimensions of transparency and truthfulness, central pillars the medical profession is obliged to uphold, especially to meet standards of informed consent.

This exchange serves as clear evidence of Latour’s (1993) Great Divide at work in the ability of campaign scholars to not address questions considered medical. And, this exchange shows the ideational power of what I conceptualize as the discourse of donation as well as a strong resistance to exposing debates over alienability to the public. As mentioned in chapter 5, TGLN shines a spotlight on Ontario and Canada’s first DCD donor family, Emile and Beth Therien, with their blessing, when the topic of DCD is raised. Emile Therien’s adoption of organ donor advocacy work has facilitated an emphasis on DCD as an opportunity otherwise denied. In the 2010

collaborative press release identified above, Emile Therien is quoted, “ ‘Stopping DCD in Canada would be a step backwards, and a real blow to those who are on wait-lists for organs, and to families who want to see something positive come out of the loss of a loved one’ ” (Canadian Blood Services et al., 2010).

Central aspects to this controversy are medical authority and knowledge, especially what we might call the politics of public information. In defense of DCD, the lead author of the DCD guidelines, Dr. Sam Shemie, is seen in the CBC documentary stating, “we do a good job” (CBC, 2014). What he conveys is that medical professionals can be trusted. In 2010, 2012 and 2014, what we also see here is a sensitivity of information within deceased donor *community altruism*. The substance of a debate over what constitutes death does threaten transplantation: the greater the degree of donor protection, the lesser the alienability of the organ. As we saw in chapter 5, the focus on consent isolates what is at stake to a question of generosity (as an obligation to community) that presumes alienability. People are not asked ‘when are you dead,’ but ‘will you donate’? Yet, we see in this controversy among experts that what is at stake is almost less the substance of a debate over death than its feared effect: that such a debate will dissuade people from consenting to donate their organs. Part of what may contribute to the disjuncture of ‘structured forgetting,’ then, is the way in which bringing deceased donors into view outside the lens of recipient-centrism has the potential to undermine altruism.

6.2.2 Seeing the Pool as a Population

In this section I present a competing explanation for the organ shortage that belies the claims of the discourse of donation, and I expose a closely related debate that has remained outside of public view. The debate reveals the way in which the deflection of attention from alienability that I argue

works at the individual level (as seen above) also works at the macro-level to obscure deceased donors as a population. This has been suggested throughout the preceding chapters, especially in two places: I described a piece of this contestation in chapter 1 to open the thesis; and, in chapter 5 I demonstrated how the size of the pool of potential deceased donors was measured in a public policy report in 1985 but not in the reports produced in 2000, 2007 and 2009. Further, that during the period of 2000-2014, the pool is presumed to exist and be of a sufficient size to not present a barrier to the supply strategies repeatedly recommended and followed. The dominant strategies I refer to as ‘the two standard solutions’ of consent and hospital efficacy, were located within my conceptual framework as techniques of conversion, shifting potential donors to actual donors. Last, I showed the discourse of donation was not interrupted in any way by the changes made by experts, between 2005 and 2007, to expand the boundaries that define the pools of potential deceased and potential living donors.

A central question for any public policy endeavour is to ask: how amenable to intervention is this problem? As chapter 5 amply illustrates, the answer to this question is “very amenable” based on the evidence using donors per millions to show that other countries have higher rates of donation. And, given that every single organ retrieved will save or improve one or more lives, and that there are refusals to donate (as we saw above, in Table 14, of approximately 3 of out every 10 requests in 2012), higher consent rates will make a difference. But there is strong evidence to show that the magnitude of difference that consent will make is not as great as is suggested by the discourse of donation.

When I specifically asked key informants why there is a shortage of organs, a few experts did not rely on the two standard solutions of consent or hospital efficacy. Their explanations looked to the mortality profile of potential donors. A member of TGLN’s senior staff, in particular,

emphasized the importance of appreciating epidemiology in assessing the size of the potential donor pool: “I think, on a per capita basis, the number of potential donors has decreased from what it was twenty years ago” (OPO1). The paradox was explained as follows:

We know what the major causes of death are that lead to organ donation: motor vehicle accidents, work related accidents, traffic accidents, failed suicide attempts, gunshot wounds, about half are traumatic accidents. The other half are brain aneurisms and strokes. And there are some more unusual circumstances. But 90% are those broad groupings.

Well, we know in Canada that when we introduced seatbelt legislation, when we introduced helmet legislation for bicycles and motorcycles, when we introduced lower speed limits, as the price of gasoline has gone up, all of those factors reduce highway deaths. There is published literature about that.

We know, for example, that the stroke prevention strategy. What’s it called? There is a drug AST or something? If you have an incipient stroke and you can get to an Emerg and they can administer this drug, it will save your life. Ontario invested a lot of money six to seven years ago in making that capability available, educating ambulance drivers to take people to designated hospitals. Our death rate from stroke has reduced over the last decade as a result of that. All our efforts to improve heart health, that has had an impact on stroke deaths (OPO1).

This account, while anecdotal, supports David Baxter’s research finding that the size of the pool matters, and, in Canada, it is shrinking. It also captures what George Annas called in 1988, “the paradoxes of organ transplantation” (as quoted in chapter 2). What matters are mortality rates for causes of death that lead to potential donor status. As we saw in chapter 4, what creates the pool of potential deceased donors are catastrophic neurological conditions, the prevalence of which is influenced by efforts to prevent injury and illness and treatment outcomes. How people die, and how many people die in what way, varies by place; it is a function of the social organization of society.

Not until 2013 has there been any research in Canada to test David Baxter’s finding that the deceased donor pool is shrinking. As mentioned earlier, it was notably the expansion of the deceased donor pool, and disagreement with DCD as death, that raised the profile of the pool

enough to inspire research on the dimensions and trends influencing the size of the catastrophic neurological condition population (aka, potential donor population). Following his 2006 critique of DCD, Dr. Christopher Doig and colleagues conducted research in Southern Alberta on the potential donor pool using brain death criteria. This team of physicians confirmed that the deceased donor pool, using brain death as the eligibility criteria, is shrinking slightly (Doig, 2006; A. Kramer & Zygun, 2013; A. H. Kramer, Zygun, Doig, & Zuege, 2013).

The focus of the discourse of donation is steadfastly on the point-of-contact of organ exchange. But, these findings point to the macro-level relationality of donors to recipients: how society is organized to prevent injuries and illness also has a bearing, along with treatment success, on the number of organs available. Appendix A from the profile of deceased donors presented in chapter 4 identifies the primary cause of death among Ontario's 4,616 deceased donors (1967-2010): spontaneous intracranial hemorrhage, motor vehicle accident, head trauma, anoxia/hypoxia. Kramer, Zygun, Doig and Zuege (A. H. Kramer et al., 2013: E838) render visible Annas' paradox of transplantation in the interpretation of their findings, and the link between the two sets of patients, potential donors and potential recipients, obscured the discourse of donation:

The proportion of patients with brain injury who progress to neurologic death has decreased over time, especially among those with head trauma. This finding may reflect positive developments in the prevention and care of brain injury. However, organ donation after neurologic death represents the major source of organs for transplantation. Thus, these findings *may help explain the relatively stagnant rates of deceased organ donation in some regions of Canada, which in turn has important implications for the care of patients with end-stage organ failure.*

The more successful physicians are in saving the lives of patients with head trauma, the less likely potential recipients will receive an organ in time to save their life.

What I also learned through my interviews was that another contributor to the shortage are aspects of demand that are not common knowledge. Organ donation campaigns promote the idea that demand for kidneys is not only steadily rising but also reaching crisis levels, and they often profile young transplant candidates or recipients. To my surprise, I was told on two separate occasions, “It’s actually not true that the demand for kidney transplantation is going up” (Tx3, OPO1). It is received wisdom that since 1980, the incidence and prevalence of end-stage renal disease (ESRD) increased throughout the world and continues to do so. But in Canada, for all but older patients, this trend reached a peak in 2001 and then plateaued over the course of the decade (Canadian Institute for Health Information, 2009: 23). Senior staff of TGLN told me that, “the only real growth in incidence of dialysis in the last five years has been in the elderly. In the younger populations, it’s pretty much level now” (OPO1). Not only has the incidence rate for ESRD remained relatively constant from 2001–2009, “those aged twenty to forty-four saw a 7% decline in new diagnoses of ESRD over the decade” (Canadian Institute for Health Information, 2009: 5).

Further, a central premise in the search for more organs is that demand causes the shortage of organs. In other words, there is a higher demand than supply and therefore supply must rise to solve the problem; all strategies seek to raise supply. But is transplantation demand-driven? A senior staff person at TGLN said,

There isn’t a jurisdiction in the world that doesn’t have a waiting list for transplantation. And, what you see is that in a jurisdiction where more organs are available, the physicians become less restrictive in terms of their criteria for putting people on (OPO1).

This observation substantiates another of George Annas’ paradoxes of transplantation (described in chapter 2), this time the claim that the organ shortage is a social construction. In the same fashion as becoming an organ donor, becoming a transplant candidate (meeting eligibility criteria and

being put on the waiting list) is not merely a matter of failing biology; it is the product of social decisions, of practitioner behaviour, and institutional interests. There are two ways in which supply drives the waiting list for organ transplants. In Ontario, a 2009 study found significant variation between regions in terms of the percentage of dialysis patients listed as kidney transplant candidates (Zaltzman, 2006). The same TGLN staff person saw this not necessarily reflecting epidemiological trends but physician listing behaviour (OPO 1). What this suggests is that meeting demand is elusive. Many facets of this explanation for the organ shortage deserve further research.

6.2.2a Making the Impossible Look Possible: The Politics of Measurement

Although the pool of potential donors is not recognized as a significant variable in the public realm – due, I argue, to the dominance of the discourse of donation – there is solid evidence of a deep-rooted debate over recognizing the size of the pool within the transplant community dating back to the late 1990s. The debate revolves around how to measure the number of organ donors, pitting organ procurement organizations against transplant providers.

As described in the opening story of the thesis, mere months after the release of Premier Harris' report, in the year 2000, demographer David Baxter (Baxter, 2000b; Baxter & Smerdon, 2000a) released two reports that included a critique of DPMP as addressed in Chapter 3. Harris claimed that not only was the organ shortage a crisis but that this was especially the case in Ontario where the annual deceased organ donor rate at 14.1 donors per million population (DPMP) compared to 33.8 in Pennsylvania and 33.6 in Spain (Boyle, 2000; Ontario, 2000). However, by age-standardizing the populations, calculating mortality patterns and adjusting for definitional differences in the way donors are counted, Baxter found that, to the contrary, Ontario and Canada's deceased donor rate was the same as the United States and Spain, indicating that the system was

already performing on par with top jurisdictions. At 43.2 donors per 1000 eligible deaths, Ontario was above the national average (Baxter, 2000b). Room to increase the number of deceased donors was limited especially given evidence that the potential deceased donor pool was diminishing as morality rates for catastrophic neurological conditions declined. In an interview conducted for this study, Baxter explained that the “Canada the underachiever” claim was based on an “intellectually dishonest” metric of donors per million population. By using a live population as the denominator, the effect is to deny dependence on mortality trends. “You could improve the organ donor system to perfection and still have a drop in the number of deceased donors.”

The critique of the *donors per million population* measure is that it puts the entire population in the pool of potential donors without acknowledging donor eligibility criteria, namely death. This is inconsistent with the TGLN acknowledgment, in select places, that only 1–3% of the population will die in a manner that leads to organ donation eligibility—that is, die from brain death or cardiac death, in hospital, with healthy organs (and in the absence of a coroner’s investigation). Like the message in the discourse of donation suggesting that advanced consent to organ donation will in and of itself alleviate the suffering of transplant candidates, the ‘per million population’ donor rate shown in comparison to other jurisdictions suggests that significantly greater organ acquisition is possible without making any changes to the boundaries of the deceased donor pool.

Baxter is a demographer who regularly produces reports on a range of subjects for policymakers. In an interview, he told me about how his critique emerged.

In doing this work...I kept running across this donors per million population number and I said, ‘I’m sorry, this is a throwback to pre-historic times. It just doesn’t make any sense. But, particularly, *it doesn’t make any sense in a policy context.*’ And, so, I wrote in the first report, it was almost like a digression, it was like, ‘oh, and by the way, don’t do this.’ *That got people very exercised.* They didn’t care about the supply and demand issue, they cared that I was attacking donors per million.

And I said, ‘why do people care?’ and they said, ‘the reality is that Canada has a dismal donor rate, Canadians are not generous, they have the worst donation rate in the developed world. They don't have the incredible donation rate of Spain or the United States.’ So [I said], ‘how can you say that?’ [They said], ‘look at our donors per million population.’ And I said, ‘but that's stupid to look at.’

Baxter and his colleague did their work on organ donation and transplantation *pro bono*. They were outsiders to the world of transplantation and had nothing at stake. He told me that with a background in engineering, where numbers matter, he cared about getting the numbers right. Baxter and his colleague found that Canada had just as good an organ donation system, with a similar organ donor rate as Spain and the United States, once the populations were adjusted for age and the mortality rates were taken into account.⁶¹ When Baxter presented the findings to transplant physicians and surgeons, around the year 2000, he was not well received.

I presented this in Japan. The Spanish delegation and a number of Canadians walked out. I presented it at a transplant conference in Jamaica. At end of my presentation, the head of the host organization asked the doctors to vote on whether I was right or not. They voted that I was wrong. He said, ‘you must be wrong.’ ...Meeting the CCDT, I gave a presentation about evaluation methodology and was personally attacked. And, to the point that one of the other people at the conference had to take a man aside to say, ‘you can't attack someone personally about research methodology’. I don't care but people are *deeply, deeply, deeply stressed*. I don't know why. It seems very simple to me...You cannot answer the questions you want to answer about policy using this as an evaluative measure. It seems so patently obvious from a research methodology point of view.

⁶¹ This finding would only be strengthened by the other critique of the DPMP measure which is inconsistency in how it is defined and calculated in different countries. Canada counts a donor only if at least one organ is used in transplant surgery. The United States and Spain include donors who are categorized as such but whose organs are not used (for a variety of reasons).

Subsequent to our interview, I discovered that the DPMP issue was raised a few years earlier in the United States. Baxter appeared unaware of this history and did not use it in any of his three reports on the topic.

In 1997, the American Government Accounting Office issued a report titled *Organ Procurement Organizations: Alternatives to More Accurately Assess Performance* (Government Accounting Office, 1997). The report was a response to some organ procurement organizations claiming performance misrepresentation. A few academic articles followed in 1998 and 1999. In a 2003 editorial, two experts explained:

Although it is easily calculated, DPMP is a crude measure based upon an irrelevant census of the living. No meaningful comparison can be made unless a precise denominator (the number of deceased patients who are medically suitable to be an organ donor) is determined or at least estimated. In this donor potential framework, the reference base is appropriately the dead. Otherwise, *evaluating OPO performance or a nation's organ donation performance [...] based on DPMP misrepresents some Donation Service Areas as underachievers, when in fact they simply have fewer potential donors* (Luskin & Delmonico, 2003: 1185, emphasis added).

All agreed that DPMP is an inadequate measure. Baxter put it more bluntly in our interview by saying both that, “this measure fails grade nine math,” and, on a serious note, that, “it is intellectually dishonest.”

In 2003, an American scholar named Ellen Sheehy and her colleagues published findings from a notable study that was funded by the United Network for Organ Sharing—the United States’ central organ procurement organization. Based on a three-year chart review of thirty-six OPO catchment areas in the United States, the study found evidence of limits to the deceased donor organ supply:

...even in an ideal world in which all brain-dead potential donors became actual donors and the demand for organs remained constant rather than increasing, the supply of

organs from brain-dead donors *could not* meet the needs of all the patients on waiting lists (Sheehy et al., 2003: 673, emphasis added).

This evidence put a further dent in the impression made by the discourse of donation and use of DPMP that the problem of an organ shortage can be solved. It supports the competing explanation for the organ shortage, above, and extends the American Government Accounting Office and Baxter's findings. This study may well have contributed to the expansion of deceased and living donor eligibility criteria in CCDT led forums of experts between 2005 and 2007.

Based on my research data, Baxter's challenge of the conventional measure was clearly well known within the transplantation community in Canada. It led to three Canadian organizations attempting to establish a better measure of the deceased donor rate than *donors per million population*: the national statistical agency, the Canadian Organ Replacement Register; the CCDT; and, TGLN. Only TGLN was successful in establishing and operationalizing a new measure: the conversion rate. As I detail below, using evidence from special and annual reports, even though a conversion rate was established, the DPMP measure did not disappear. This was evident in the persistent use of DPMP identified in chapter 5. I present evidence to account for the retention of the discredited measure that suggests that use of the DPMP is ideologically motivated.

6.2.2b *Intermediary Dissonance*

A year after Baxter's reports, in 2001, the Canadian Organ Replacement Register responded by releasing their own report on the matter with the sub-title "Estimating Cadaveric Organ Donors for Canada." Confirming the legitimacy of Baxter's critique, the statistical agency agreed that,

Cadaveric organ donation has been traditionally measured in terms of rates of donors per million population, an internationally used standard. It is, however, more

informative to compute cadaveric organ donation rates using a population that has some immediate potential for being a donor (CORR, 2001: v).

The use of DPMP is recognized to hold *a statistical bias* but its use is justified because it is an international standard. In his second report, Baxter called this measure “inappropriate, misleading and unnecessary” (Baxter, 2000b: iv). Nevertheless, the Canadian Organ Replacement Register continued to report the deceased donor rate using DPMP, but now with a caveat acknowledging the issues with this measure. Only with an enhancement to their website around 2012 did the organization start to take a significant step towards presenting a profile of organ exchange in the country using a conversion measure. This shift was to step beyond raw numbers to show figures for ‘potential’ and ‘actual’ donors in “e-Stat” tables that are posted layers deep on their website.⁶²

Similarly, in its first annual report, the new national agency, the CCDT, took up the measurement issue. In fact, three of four annual reports produced during its lifespan, from 2002–2006, included a description of work underway to “determine a realistic potential donor rate” (CCDT, 2003: 4). But this work was not completed. In 2003, the task of developing “a method that is simple, reliable, and reproducible to define, measure, and monitor donation rates,” was the first of three broad priorities:

Currently the number of actual donors per million population is the most widely reported measure of organ procurement. However, this figure does not indicate the number of potential donors in the population. *The establishment and adoption of a realistic potential donation rate for Canada will provide a benchmark against which actual donations can be measured.* This will allow effective analyses of any gaps between potential and actual donation rates, and will allow for a measure to improve donation rates (CCDT, 2003: 4, emphasis added).

⁶² ‘Potential’ donor in these tables refers, however, to ‘potential donors’ who do not become ‘actual donors’ (not, as TGLN uses the measure, of the larger pool from which ‘actual’ donors are a subset).

The measure is hoped to be easily understood and readily reproducible in all jurisdictions. However, very little was written about this work in the subsequent two reports and by 2006 there was no mention of it in the annual report. This was in spite of the one-line descriptor in 2004 annual report anticipating a first report that would “enhance and enable accountability and evaluation of donation” (CCDT, 2004: 10).

Unlike the Canadian Organ Replacement Register and CCDT, TGLN had its reputation on the line regarding the issue of measuring the deceased donor rate. Each year, the conversion metric established by TGLN moves progressively out of the text and into the appendix of annual reports to serve as the standard and primary measure of performance for the organization (the other being transplant yield per deceased donor). Deceased donors per million, as a measure of the donor rate, does not appear once in any of the TGLN annual reports spanning from 2002 to 2012. The significance of the conversion rate is both to establish a performance measure that OPOs deem fair given their inability to influence the size of the potential deceased donor pool, and, through each isolated variable, for these organizations to try to pinpoint where in their work conversion did not occur and might be improved. For example, in the 2006 report, medical suitability and coroner office jurisdiction over bodies for autopsy, were identified as obstacles to reaching TGLN’s annual donor target.

In light of this contestation, the efforts by two national organizations in this direction, and the success of one organization to create a new, more meaningful measure, the persistent use of DPMP raises two questions. First, why has it remained the conventional measure? The conversion rate and the nuanced data it isolates was not used to inform either the 2006 Citizen’s Panel report, or the 2009 Wait Times report. Second, why does this measure remain in the shadows when it could serve as the measuring stick for organ donation? A key informant from TGLN explained,

If you only rely on donors per million you are blind to the underlying epidemiology. And, to insist that Ontario could match Georgia, or Spain or Chicago is to be naïve. The transplanters don't like to admit that. I've heard stories of Txers getting very angry when social scientists try to show them this data. They just refuse to. I think you are hard pressed to find a transplanter who would accept the value of that analysis. Their argument is that there've got to be lots of potential cases out there, you are just not trying hard enough to find them. 'People are dying every day.' They miss the subtlety. So that is frustrating, yeah.

You know, we said, when Mike Harris set this Millennium Challenge of doubling the donor rate, he didn't have an epidemiologist. And, if he had, he would have known that he couldn't have done it. That is probably the best example possible of optimism.

This was consistent with Baxter's view that "transplanters cannot give up on donors per million population; it works for them" by supporting their case for more government funding, and the cause of organ donation. And, it is not out of the realm of normal. In an informal conversation with a former colleague who runs a non-profit health organization, I was told that it was standard to 'pitch' the particular cause of the organization in the spirit of, as he put it, "a capital 'A' for advocacy, and, small 's' for science." As another interviewee, Dr. Robert Conn (introduced below) said, "so, statistics, you know, numbers vary; they tell a story but often people pick the story they want to tell and find the numbers to support it."

But the implications are significant. As Baxter identified in our interview, "DPMP allows you to not ask really hard questions." using the conversion rate doesn't allow you to push the boundaries. We've spent all this money and the donor rate did not improve. This is a policy failure. "they don't see themselves as winning from deeply probing for explanations" Someone has to say: "justify using that measure." DPMP allows you to say, "we have a lousy transplant system instead of 'my son died because yours didn't.'" As we saw in chapter 5, it also allows journalists, like CBC's Michael Enright, to argue that we must introduce monetary incentives.

I learned in my interviews that TGLN did make one intervention in one public policy report to broaden the scope of explanations for the deceased donor rate. Of three public reports produced in 2000, 2007 and 2009, TGLN was a participant in only one, the Wait Times Report of 2009. This report, led by Dr. Gary Levy, a liver transplant physician, does include one table showing the conversion rate and notes that Ontario's conversion rate is higher, at 75.6% than a United States average conversion rate of 71.1% in 2008-2009. Yet, there is no further analysis and the executive summary states, "Ontario's deceased donation rate per million population is below the Canadian average and below many other jurisdictions. The fact remains: wait times for transplantation will continue to be long unless there are more organ donors." One component of four multi-step recommendations – that I was told TGLN insisted be included – is an epidemiological study of the deceased donor population (OPO1). In keeping with the tone and content of the 2009 report, this was described as a study of *donor characteristics* tied to public awareness and opportunities to donate rather than accountability for performance.

My point-of-departure in analyzing this debate among intermediaries is to first identify a comparative observation. Above, in the public contestation over death, we see that intermediary organizations stand in solidarity by releasing a collaborative press release defending DCD as death. In this debate the same parties are divided. And, yet, objection to the use of DPMP is minimal even though it works precisely in the way the American Accounting Office found, to misrepresent Ontario as an underachiever, "when in fact they simply have fewer potential donors." (Luskin & Delmonico, 2003). As we saw in the previous chapter, this was also warned of in the 2007 Citizen's Panel report. That the ability to achieve deceased donor goals,

...will require realistic expectations based on our health facts in Ontario. Failure to do so will ensure a permanent inability to achieve these goals and the resultant

assignment of inappropriate blame (Ontario, 2007: 13, emphasis added).

This brings the analysis to another case of ‘seeing’ donors that provides insight on the contributors to the deflection of attention of ‘structured forgetting’.

6.3 Crossing Over: Seeing Deceased Donors’ Deaths as Unnecessary

A different explanation for the disjuncture of *structured forgetting* arises from the story of Dr. Robert Conn. He came to see the lives of deceased donors as preventable. What led to his dissent and departure from transplantation identifies a structural barrier to seeing organ origins and a cultural explanation of a different sort.

Years prior to this research, I noticed the story of Dr. Robert Conn, a former pediatric heart transplant surgeon who quit transplantation to found, in 1992, a national injury prevention organization based in Toronto. The newsletter I read described his tale as follows:

He saw that the majority of heart donors were young people who died as a result of severe injuries. He began to question the cause of these injuries, and after researching the subject, concluded that 90 percent of all injuries were preventable. He also began to *realize that he could save more lives by focusing his energies on injury prevention than he could by remaining in the operating room*. After much soul searching, he...started the SMARTRISK Foundation (Schizkoske, 1999, emphasis added).

For this reason, I interviewed him for this study. I asked him what led to his uncharacteristic departure from a prestigious career. He described a confluence of factors that led to an epiphany, described above. First was his interest in the healthcare system and noticing the significance of injuries (which were not even recorded in the late 1980s in the International Code of Diseases). Injuries were the cause of backlogs in operating theatre schedules and were a high cost on the

system.⁶³ This was coupled with an uncommon experience in his transplantation training. As identified in chapter 3, one of the rules of altruism is the separate teams rule whereby the transplant team can have no connection from the treating team of intensivists in the ICU/CCU trying to save the patients' life. Conn described this as a strict workplace structural division of labour. But, he also explained to me something I did not know: at the time of his training, transplant surgeons did not come into contact with the donor at all. The work of removing the organs was performed by procurement specialist technicians.⁶⁴ The role of transplant surgeons was implantation which meant a first encounter with the organ, not the donor. However, Conn's mentor in Alabama followed an unconventional method by insisting that transplant surgeons-in-training do the work of organ removal.

So, you know, I'd go and get the organs. *And, I'd never, ever stopped to think where the hearts come from. I'd always been focussed on the miracle of transplantation...* [and] every day I was going out and getting hearts and sitting in the corner of the operating room while the other teams harvested their organs...And, I'd sit there and, the patient's draped. You'd have no idea who they were. And, I'd read their chart. And, I just remember reading story, after story, after story of primarily young people who were very healthy in one moment, and then, as a result of being hurt, were brain dead the next. And, just thinking, 'this is crazy, I'm taking hearts out of people that shouldn't be dying.' And, eh, and I remember feeling one day just a bit embarrassed that I'd never stopped to think about where the hearts come from, that I'd be focussed on the miracle of transplantation.

Conn 'saw' donors and learned about them by coming into contact with them and it had a profound effect on his career path. He shifted to looking at the antecedent events of injury prior to hospital

⁶³ He told me, "It's actually not the ones that are dying that cost money it's the ones that get injured and survive."

⁶⁴ Conn explained that this category of well-trained surgical technician assistants was created to provide employment for primarily young men trained as medics in the Vietnam war. It was his impression that procurement assistant training was commencing in Canada. My efforts to ascertain who, exactly, removes the organs in Ontario was unfruitful.

admission. “And I remember, driving actually up to Toronto after my time in Alabama, thinking well if something is predictable it should be preventable.”

Conn’s breach of the structural divide led him to see donor deaths as unnecessary. What led him to see and think about where the hearts came from also supports the line of thinking followed by Nancy Scheper-Hughes (quoted in chapter 2) when she identified the privacy rule as an unintended contributor to the structured forgetting of the origins of deceased donor organs. Conn acknowledged in our interview, that, “there was a structural division there...The mindset was that there was a conflict there...So the people interested in transplant, [who are] trying to get more donors, are in a silo and they’re not necessarily thinking broadly.”

In Conn’s view, another contributor to the deflection of attention is what he described as a cultural aversion to identifying deaths by injury as preventable. He added that, “And, donation stories make good stories, they’re – I mean you can focus on the happy side of the donation.” From his perspective working on the prevention of unintentional injury,

...there’s this weird paradigm when people die of injury where everybody pretends that its, um, people kinda pretend that it’s somehow meant to be or it’s some part of a bigger plan as a way of providing comfort to people, and a real hesitation to talk about the circumstances leading up to it...I think maybe we don’t talk about the stories about how people end up being donors because it illustrates, you know, uh, the role people might play in their own deaths. *And it substitutes what everybody wants to cast as a happy story of giving into a sad story of bad decisions and remorse.* And, we’re not comfortable, in this society, in talking about peoples’ bad decisions.

People used to always say to me – they didn’t ask after a while – but initially they would say, you know, how could you be doing this? You know, how come you’re not helping to transplant organs? And, aren’t your colleagues going to be angry with you because *you’re trying to put them out of business?* (emphasis added)

The link of donors to recipients is made in the last sentence, recognizing not only tension but once again the paradox of transplantation. By this account, the culture of donation takes advantage of

another aspect of our contemporary culture which is the acceptance of deaths by injury. The happy story, and, the opportunity through donation to give death meaning further close the door on thinking about deceased donors and taking action to prevent these deaths. Along with Scheper-Hughes and Sharp (described in chapter 1, the introduction), I have been deeply disturbed by the contortions of positive meaning that are attributed to preventable deaths, especially from the violence of intentional injury.

For example, in legal scholar and pro-regulated market advocate, Michele Goodwin's (2006: 10) book titled *Black Markets: The Supply and Demand of Body Parts*, published by Cambridge University Press, devotes the first four pages to drawing the connection between a donor and recipient that provokes the question, as she puts it, of "from whom will we capture organs and to whom will they go?". In her example of organ exchange, the donor, William Michael Lucas, 34, died in 1993 of violence. His heart and liver went to the then Governor of Pennsylvania, Robert Casey. Goodwin acknowledges that this was an exchange of a young Black man living where the, "state could not or did not resuscitate his dying community, ravaged by poverty, unemployment, drugs, and lacking in healthcare," compared to Casey, "a 61-year-old White male" (Goodwin, 2006: 2). She quotes a social commentator from the time characterizing this exchange as follows:

"so it was that a man marked by every scourge of his times – violence, drugs, joblessness, racism – saved the life of the governor of Pennsylvania." The 'tragic irony,' he notes, 'was that it was supposed to be the other way around' (Goodwin, 2006: 2)

A letter to the editor included in her book captures a member of the public expressing "umbrage" that, "when public servants become recipients of the organs of violent-crime victims, one is left wondering, 'To whom is protection being rendered?'" (Goodwin, 2006: xviii).

This example of the hierarchy of society reinforced through deceased donor organ exchange is worse than the fear Margaret Lock (1995c: 392) expressed (as identified in chapter 2), that “because a ‘flow’ of organs must be sustained, there is little incentive to work actively against the violence of North American society.” Goodwin’s holistic start drops the donor and takes up the position of potential recipients, especially African Americans, whom – if wait-listed – make up the bulk of transplant wait-lists in the United States, especially for kidneys. It is exclusively the plight of transplant candidates that shapes her research agenda even though her exemplary case raises the question of whether African Americans are suffering more than others on both sides of the donor-recipient equation. Why only fight the cause of potential recipients? Notably, a full chapter providing statistical data from the United Network for Organ Sharing to demonstrate the shortfall between the demand and supply of deceased donor organs makes no mention of the size of the deceased donor pool. Again the presumption of a pool is the basis for laying all of the blame for organ shortages on low rates of consent to donation. Goodwin’s championing the cause of African Americans who need organs is well-founded but is compromised, in my view, by her choice to abandon African Americans who become deceased donors.

I would argue that although there is an understanding as some level of a paradoxical relationality between donors and recipients in deceased donation – as demonstrated in the last sentence of Dr. Conn quote above, that he was “*trying to put them out of business*” – preventing death through transplantation gained greater political salience during this period than efforts to prevent death from Catastrophic Neurological Conditions. In fact, efforts at prevention, overall, are barely on the political agenda. Yet, there is a clear case for more effort devoted to preventing End-Stage Renal Disease which, paradoxically involves preventing the same primary diseases that cause Spontaneous Intracranial Hemorrhage, identified in Appendix A as the number one

Catastrophic Neurological Condition that led to deceased donation. Contributors to both are diabetes and hypertension, and both of these conditions are preventable (except Type 1 diabetes). A full analysis of reasons for investment in transplantation, especially as a public policy decision that outstrips other investments, including the prevention of injury (unintentional and intentional), is beyond the scope of this thesis. Here I advance the claim of a *structured forgetting*, and contribute to scholarship on this phenomenon by identifying how the disjuncture arises and is sustained.

6.4 Conclusion

This chapter has provided a contrasting viewpoint and analysis of deceased donor *community altruism* than was provided in chapter 5. I demonstrated in this chapter the ways in which recipient-centric-donor protection tension arises, and identified several contributors to the disjuncture of *structured forgetting*, such as the use of the *donors per million population* measure, and the suppression of dissent.

In the first section, I detailed TGLN's work with hospitals to establish donation services. The actors and systems were described followed by an explanation of the conversion rate measurement TGLN developed to monitor organizational performance. Importantly, I presented research findings that discredit the exigencies of the discourse of donation. In chapter 5 these claims of system blame were critiqued using discourse analysis, for example by identifying a disclaimer of doubt in all three public policy reports. The original analysis, using TGLN data, in section 6.1.3 adds quantitative evidence to further substantiate my argument that customary claims about how to increase organ donation deflect attention from the limits of alienability. When

transplant physicians say, “people die in hospital every day,” implying (or saying outright), “there are more organs ‘out there,’” the correct answer is: yes, there are some but not enough.

Drawing on the competing explanation for the organ shortage by Baxter, TGLN’s approach to measuring system performance and others, a far more modest picture emerged: Ontario’s deceased donor system has improved over time, and performed at a level of 53.2% efficacy over the period of 2008-2012. Further, it was shown that while there is room for improvement through the conversion of potential to actual donors, the size of the donor pool from 2008-2012 was not large enough to provide kidneys to every End-Stage Renal Disease patient on the deceased donor wait list. What this means is that techniques of conversion bear an influence – what I called the two standard solutions of consent and hospital efficacy – but are limited by the trends in mortality for patients with Catastrophic Neurological Conditions. The impression given in using the *donors per million* metric is misleading. Ignoring conversion and mortality data allow the situation to look more extreme, and more amenable to intervention. Section 6.2.2 provided some explanations for the continued use of the *donors per million measure* by demonstrating that measuring deceased donors and the system of organ donation are political issues that strain intermediary relations. And, yet, public critique remains absent. There are, in effect, two parallel ways of measuring organ donation, DPMP is popularly used in the public realm and to inform public policy while different picture the conversion rate provides remains in the shadows. I return to the implications of these findings to contemporary debates on kidney exchange in the conclusion of the thesis. It is important to also note that a far more elaborate and quantifiable analysis than was possible here is called for to examine, following Keiran Healy’s work, what variables make a difference in raising the donor rate, among other policy considerations.

Throughout this chapter, I took the analysis a step further in pointing to a second layer of controversy in the individual and population-level of ‘seeing’ limits to the alienability of deceased donors. An aspect of the social relations of exchange that is heightened in an explicit consent regime is the need to persuade owners of organs to consent to donation. This requirement of converting potential donors into actual donors creates an incentive to present the positive and a disincentive to present what is perceived to be dissuasive. We see in section 6.2.1 a rare instance of direct criticism of the kind of discourse of donation messages in media campaigns of the kind detailed in chapter 5. I draw attention to this second layer of controversy because I see it as contributing to our understanding of the deflection of attention, and, because along with all debates in this chapter, what is known and seen carry weighty implications in these life and death matters. I return to this in the conclusion of the thesis.

Chapter 7 Cash for Kidneys and the Rise of Living Donor Protection

The next two chapters address what has enabled and inhibited living donor kidney exchanges at Ontario transplant centres, between 2000-2014, while keeping in mind the practice of Ontarians buying kidneys at transplant centres in other countries. Following a brief overview of living donation, the examination that follows is presented in two chapters divided by level-of-analysis to reflect, in the chapter, the continuation of boundary work at the supranational and national levels demarcating “ethical” and “legitimate” from “unethical” and “illegitimate” kidney exchanges. And, in chapter 8, how kidney exchanges work in practice at the local and national/provincial levels. We see that coming to know the donor is key to upholding “ethical” living donor kidney exchanges at transplant centres in Ontario, while mostly pliable but also rigid rules are pushed to loosen potential living donor eligibility criteria – in other words, to expand the pool of potential living donors to increase the volume of kidneys available.

My overarching argument that sustains both chapters is that processes of demarcation in statements and guidelines, upholding guidelines in practice and actual changes expanding living donor eligibility criteria reflect the inherent tension between donor-intermediary-recipient and the recipient-centric push to acquire more organs. As transplant abuses continue, so does a donor-protection reaction which I detail. While the moral imperative to increase transplant volume remains powerful, the dominant ‘discourse of donation’ that I argue deflects attention from donors in deceased donation is more striated in living donation. A central difference is in the stakes of alienability. For deceased donation, the legitimacy of removing kidneys is determined by death; for living donation, legitimacy rests on the claim that a balance is struck between beneficence and

maleficence. Determining minimal and reasonable risk to a living donor is acknowledged among transplant medical providers to carry a degree of subjective interpretation.

What is claimed to be “ethical” in living donation are policies and practices that work within the original rules established to govern organ exchange detailed in chapter 3. However, the quest we see here is one of ‘finding the line’ that allows transplantation to expand “ethically”. The visible contestation is over the terms of exchange of altruism while, again, the less visible ‘pliable’ rules of alienability are staked out and shift largely out of public view.

This chapter opens by documenting the emergence of what can be considered rules that demarcate ethical supply strategies for living donors at both the international and Canadian levels. This resumes the thread started in chapter 3 regarding the effort to manage the threat of kidneys holding more value than persons. While initiated in the mid-1980s, the flourishing of an international, profit-making market (in other words commercial mode of exchange) for living unrelated donors provoked two different types of responses: (1) the rise of an anti-transplant abuse campaign⁶⁵; and (2) medical and ethical donor protection guidelines that seek to regulate the profession. What we see is that the goal of the first response is to inhibit practices that are deemed unethical and thereby threaten the legitimacy of transplantation as a whole, and, concurrently the goal of the second response is to (again) enable expansion by establishing limit-setting rules in medical guidelines.

In the first part of the chapter, I introduce the anti-transplant abuse campaign, its origins, key actors, and strategies deployed, while also providing a critical evaluation of its impacts and

⁶⁵ The campaign targets national, international and transnational kidney and other organ exchanges deemed unethical and illegitimate. While Ontario’s kidney buyers participant in north-south exchanges, the totality of commercial and coercive exchanges move geographically in multiple directions within and across one or more borders.

challenges. Here I zero in on why in every position statement condemning transplant abuse there is a call for countries to increase the legitimate supply of organs. I discuss how, within the campaign, the recipient-centric problem of national organ shortages is prioritized, which works to undermine the adoption and enforcement of policy measures to stop transplant abuse.

In the second part of the chapter, I discuss the rise of donor protection guidelines within the international medical transplant community. I offer a short history of such guidelines and then present their contemporary incarnations, including the Canadian variant. Guideline themes and specific recommendations are addressed in turn, with an eye to their implementation challenges. I end the section by addressing inherent tensions found within the guidelines between recipient-centrism and donor protection, the negotiation of which is best described as a search for openings in the boundary around protection to donors. While transplantation in Ontario remains the focus of the thesis, this chapter highlights how the drawing of the line between recipient-centrism and donor protection at the national (and provincial) level is linked to how this negotiation occurs internationally.

7.1 Kidney Exchange from Living Donors

To shift our focus to living donation, readers will recall from chapter 4 the profile of Ontario's kidney providers and description of how living donation works in Ontario. A brief recap raises a few points. First, there have been more living donors than deceased donors in Ontario on an annual basis since 1996. The vast majority of Ontario's living donors are intimates, related to recipients. Yet, as a whole, this population has become far more diverse and international. Further, the size and composition of the living donor population changed largely independent of

government intervention and quietly while deceased donation *community altruism* dominated the provincial public knowledge and policy agendas during the period of 2000-2014.

With respect to governance, there is no official intermediary parallel to the role OPOs play. Transplant centres in Ontario are relatively autonomous. Like centres around the world, they develop their own protocols based on national and supranational statements and medical practice guidelines. As we see below, relevant documents stem from the World Health Organization and World Health Assembly as well as the international transplantation organization introduced earlier, The Transplantation Society, and ad hoc collaborations, the Bellagio Task Force Report on Transplantation, the (almost exclusively American) Live Organ Donor Consensus Group, and participants in the International Summit that produced the Declaration of Istanbul. Canadian centres are also guided by relevant documents released by the Canadian Society of Transplantation, Canadian Society of Nephrology and The Canadian Council for Donation and Transplantation (2002-2006).

Third, as we saw in chapter 4, living donor exchanges are conventionally – and still predominantly in Ontario – between intimates, largely close kin. For this reason, I refer to the living donor system in Ontario as *Intimate Altruism*. Theoretically, however, almost anyone could be in the pool of potential living donors. What governs kidney exchanges from living donors is thus a mix of medical and social donor eligibility criteria that are established, as we saw in chapter 3, by both rigid and pliable rules. Lastly, due the direct nature of donation, conventionally there is no generalized exhortation to donate as in deceased donation *Community Altruism*. Asking for organs happens primarily within inter-personal relations and it is intimacy that has served as the rationale for donation. We see, however, here and in chapter 8, how the pliable rules bend to

broaden who is considered an intimate and weaken this standard as a basis for potential living donor approval or rejection.

7.2 The Anti-Transplant Abuse Campaign

The first response to the international market's reliance on living unrelated donors has been the rise of the anti-transplant abuse campaign in client countries, host countries, and at the supranational level. Motivated by efforts to safeguard organ donors, this *ethical transplantation position* advocates for legislation and enforcement of commercial organ market bans while also privileging live and deceased donor community altruism. Thus through the promotion of altruistic organ exchanges, the campaign attempts to channel the organ supply away from a commerce mode of exchange.

In this section, I give an overview of the anti-transplant trafficking campaign's origins, including details of its motivations, key actors, and official statements of condemnation. I then turn to a discussion of the campaign's strategies for channelling the organ supply toward community altruism. The first approach curbs the exchange of *illegitimate* organs—those acquired through organ trafficking or transplant commercialism. The second approach promotes the exchange of *legitimate* organs by establishing or increasing the number of organs donated altruistically from live persons or deceased donors. I then move to address some of the challenges facing the anti-transplant trafficking campaign today. Finally, I conclude the section by reflecting on how discourses of blame and shame, which concentrate all efforts on fixing the national organ shortage first, serve to undermine the adoption of anti-transplant abuse policy measures.

7.2.1 Origins of the Campaign

Beginning in the 1980s and in response to evidence of commerce in organ transplantation, international and non-governmental organizations started releasing position statements condemning the commercial market for organs. These included statements first released by The Transplantation Society (1985)⁶⁶, the Council of Europe (1997), The Bellagio Task Force (1997), the UN (2000), and a series of updated statements by the World Medical Association (1985) and the World Health Organization (WHO) starting with its “Guiding Principles,” released in 1991. As a whole, these organizations articulated the position that payment for organs and tissues should be prohibited, that medical professionals should not be involved in commercial transactions, and that prisoners cannot give free consent to donate their organs. Commerce and coercion were condemned in all statements, while additional abuses were condemned as substantiating evidence emerged, most notably that organ removal was a justification for human trafficking.⁶⁷

Table 16 *International and Canadian Statements Condemning Transplant Abuse*

Year	Author	Statement
1985	The Council of The Transplantation Society	Commercialisation in Transplantation: The Problems and Some Guidelines for Practice
1991	World Health Organization	WHO Guiding Principles for Transplantation
1997	The Bellagio Task Force Report on Transplantation ⁶⁸	Bodily Integrity, and the International Traffic in Organs
2004	World Health Assembly	World Health Assembly Resolution 57.18, Human Organ and Tissue transplantation

⁶⁶ This first statement by The Transplantation Society was both a condemnation position statement and an ethical practice guideline, the contents of which are further discussed below.

⁶⁷ The Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, adopted by resolution A/RES/55/25 of 15 November 2000 at the 55th session of the United Nations General Assembly.

⁶⁸ This report was produced by a working group set up by Columbia University in New York, consisting of D.J. Rothman, E. Rose, T. Awaya, B. Cohen, A. Daar, S.L. Dzemeshevich, C.J. Lee, R. Munro, H. Reyes, S.M. Rothman, K.F. Schoen, N. Scheper-Hughes, Z. Shapira, and H. Smit.

2006	Participants in the WHO Informal Regional Consultation on Developing Organ Donation from Deceased Donors ⁶⁹	The Kuwait Statement
2008	Participants in the International Summit On Transplant Tourism and Organ Trafficking ⁷⁰	Declaration of Istanbul on Organ Trafficking and Transplant Tourism
2010	World Health Organization	WHO revised Guiding Principles on Human Cell, Tissue and Organ Transplantation
2010	John S. Gill, Aviva Goldberg, G. V. Ramesh Prasad, Marie-Chantal Fortin, Tom-Blydt Hansen, Adeera Levin, Jagbir Gill, Marcello Tonelli, Lee Anne Tibbles, Greg Knoll, Edward H. Cole, and Timothy Caulfield	Statement of Canadian Society of Transplantation and Canadian Society of Nephrology on Organ Trafficking and Transplant Tourism

In 2005, the voice of opposition to the commercial market in organs for transplantation gained significant momentum. In 2004, reports estimated that illegal organ sales comprised several thousands of the approximately 15,000 transplants from live donors that take place globally every year (Council of Europe, 2004). However, by 2007 it was more modestly estimated that 5–10% of global transplants involved organ trafficking (Shimazono, 2007). As we saw in chapter 4, there is evidence that Ontarians began participating in the commercial market in 1998, with 28 buyers between this year and 2005 (G.V. Ramesh Prasad et al., 2006). Ninety-three British Columbians also travelled outside Canada and bought kidneys between 2000 and 2007 (J. Gill et al., 2011).⁷¹

Key factors that shifted condemnation into an international anti-commerce campaign include the arrival of permanent actors and dedicated resources. As described in chapter one, Organs Watch, founded by key academic activist Dr. Nancy Scheper-Hughes, emerged following

⁶⁹ Held in Kuwait City, Kuwait, on November 26–27, 2006.

⁷⁰ Convened by The Transplantation Society and International Society of Nephrology in Istanbul, Turkey, April 30–May 2, 2008.

⁷¹ Both the Ontario and British Columbia data cover a seven year period, from 1998–2005 in Ontario and 2000–2007 in British Columbia. Given similar characteristics between the provinces, the higher rate in the latter jurisdiction gives credence to the suggestion that the Ontario figure is an underestimation.

a pioneering, early investigation in 1997, the “Bellagio Task Force on Transplantation, Bodily Integrity and the International Traffic in Organs” (Rothman et al., 1997). Research by Scheper-Hughes, Moiruzzaman, Budiani-Subari and Delmonico, reviewed in chapter 2, among others, continues to result in numerous publications drawing attention to abuses.

The WHO also took on transplantation as an area of work in 2004 following a study of key issues during a meeting of experts in Madrid and subsequent passing of resolution WHA57.18. Devoted resources were further solidified in 2007. A key turning point was also reached, at the supranational level, in 2008 with the release of “The Declaration of Istanbul on Organ Trafficking and Transplant Tourism.” The Transplantation Society and the International Society of Nephrology hosted the formative summit, attended by 150 transplant experts from around the world. This event defined and clarified the problem of profit-making and direct sales in organ exchange as three related phenomena: organ trafficking, transplant tourism, and transplant commercialism.

For anti-commerce advocates, the reasons to object to the use of money in exchange for organs include improper consent, exploitation, and poor health outcomes for both parties (D. A. Budiani-Saberi & Delmonico, 2008; Goyal, Mehta, Schneiderman, & Sehgal, 2002; Naqvi, Ali, Mazhar, Zafar, & Rizvi, 2007; Turner, 2008). As Hoeyer (2013) notes, some arguments against commerce also draw on deontological ethical positions inspired by German philosopher Immanuel Kant (see, for example, Satz, 2010). Iran is the only country with a legal, regulated commercial market, exclusive to Iranian citizens. Among the few research studies published to date, both sides of the debate draw on this unique case by emphasizing different outcomes (Ghods, 2008; Tober, 2007; J. Zargooshi, 2001). On the one hand, pro-commerce advocates highlight the advantage of the commercial market that recipients are able to find donors. On the other hand, anti-commerce

advocates point to evidence of undesirable social relations such as the normalization of additional and unregulated payments by the recipient to the donor and the unrealized expectation that the money did not change the life of the donor (Francis L Delmonico, 2007).

7.2.2 Decreasing the Exchange of Illegitimate Organs Through Legislation

The primary means employed to curb commerce of organs by the anti-transplant abuse campaign has been the introduction, strengthening, and/or enforcement of national legislation prohibiting commerce in organs for transplant. The WHO and TTS actively support efforts by national actors toward this goal and concentrate their efforts in host countries where surgeries occur. Over several years, announcements of legislation prohibiting organ sales were made in six host countries: China in 2007, Pakistan in 2007 and 2010, the Philippines in 2008, India in 2008, Egypt in 2010, and Columbia in 2008 (BBC, 2007). Several of these laws also grant medical professionals more authority and autonomy in declaring brain death and enable living donation “paired exchanges” for incompatible dyads. Other key stipulations include: (1) rules prohibiting access to organs by “foreigners”—people variably defined as not part of the nation-state as defined primarily by citizenship (secondarily by residency permission); (2) rules establishing the boundaries of the family (for example, in Egypt “family members” are limited to the 4th degree); and (3) rules excluding living unrelated donors.

In host countries, where transplant surgeries take place, there are an increasing number of criminal charges, albeit fewer convictions. For example, in Istanbul in 2007, three doctors, including Dr. Yusef Ercin Sonmez—dubbed “Dr. Vulture” by the Turkish media—and Zaki Shapira, an Israeli, were arrested and released after two months in prison (Zaman, 2007). With his fifth arrest for illegal organ trafficking, Dr. Sonmez is facing criminal charges as the lynchpin of

a broker network in Kosovo that was exposed in December 2010 (Heydarov, 2011).⁷² India's most extensive kidney transplant ring to date was exposed in 2008 with the arrest of an Indian-Canadian broker, Amit Kumar, dubbed "Dr. Horror." Kumar stands accused of forcing at gunpoint approximately 500 impoverished labourers to sell their kidneys to hundreds of wealthy Indians and foreigners over nine years at a rate of 200% profit per transplant (Gentleman, 2008; Wade & Reilly, 2010).⁷³ Also arrested were seven police officers, charged with accepting bribes from Kumar. In a recent transnational South African case, private healthcare provider Netcare was found guilty of breaching prohibitions against organ sales (BBC, 2010). A broker involved in this case is also behind bars in Brazil (see Scheper-Hughes, 2007). It is notable that potential and actual victims of organ trafficking led police to the illegal activity in the South African, Turkish, and Kosovan cases. In one case from a client country, a UK doctor lost his licence for facilitating illegal transplants that took place in India (Kerr, 2002).

There is also evidence that—like human trafficking and the sex trade—criminal prosecution of those involved in organ commerce for transplant can result in victimizing the victims (Dewey, 2008). In some cases, kidney sellers have been convicted and have served jail time. In 2008, two potential sellers served three weeks to three and a half months in Singapore jails, while in 2003, sellers in Punjab, India, who complained of being cheated by brokers, were prosecuted and served two years for making false affidavits (Chong & Khalik, 2008; Pearson, 2004). For this reason, through the Coalition for Organ Failure Solutions, commercial living donors have asserted a need for victim protection from prosecution (D. Budiani-Subari, personal

⁷² Sonmez was arrested on January 12, 2011 on charges of crimes against life and health, people smuggling, trafficking, and illegal immigration.

⁷³ It is reported that the accused was arrested in Mumbai in 1994 on charges of illegal transplants but escaped, changed his name, and relocated to Gurgaon, outside Delhi.

communication, August 30, 2010). The Council of Europe report “Trafficking in organs in Europe,” released in 2003, concurred that paid donors should not be criminalized unless they become brokers (Vermot-Mangold. G.).

On the demand side, some client countries have used legislation to prohibit citizens from becoming transplant tourists. In most client source countries, like in Canada and Australia, the law does not prohibit the arranging and/or receiving of medical services outside the country (Priest & Oziewicz, 2001; Wade & Reilly, 2010),⁷⁴ and legislation banning organ commerce only applies to surgeries performed within that territory. However, in at least one treaty, an extraterritoriality clause has been added such that the ban on organ sales applies to citizens regardless of where the surgery takes place. This is the case in a Council of Europe (2002) treaty against organ trafficking, which as of January 2011, was “entered into force” in twelve of forty-seven countries. Without evidence of breaches or enforcement, the efficacy of extraterritoriality restrictions remains unknown.

In client countries such as Canada, controlling the actions of transplant candidates goes against the grain of three decades of building public sympathy for the plight of potential recipients. This is one of the unintended consequences of the *discourse of donation* exhortation work involved in securing advanced consent for deceased donation within *community altruism*. Political will for adopting a punitive approach is therefore largely absent.

Recent attention in Canada to the negative consequences of medical tourism has coincided with calls for greater deterrence, for example as expressed in a *Globe and Mail* (2010) editorial,

⁷⁴ In Canada, commercial transaction for organs fall under provincial regulation, not the federal criminal code, and the offence carries a maximum \$1,000 fine and six months in jail. Canadian recipients do not receive reimbursement from provincial health insurance plans for transplant surgeries performed outside the country.

“Put an end to transplant tourism”. A failed attempt at the federal level to introduce an extraterritoriality clause that would have established a legal mechanism for criminalizing transplant tourists gave way to a deterrence approach. In 2008, a federal Member of Parliament introduced an extraterritoriality bill (Bill C-500); however, it did not pass the first of three readings in the House of Commons. A deterrence approach was then initiated in 2010 with the release of guidelines on the ethical and legal parameters of treating patients prior to and after transplant tourism by the Canadian Transplantation Society and Canadian Nephrology Society (John S. Gill et al., 2010). Some transplant centres also started to include the Declaration of Istanbul anti-organ trafficking education pamphlets in orientation sessions for kidney transplant candidates (DT4).

7.2.3 Increasing the Supply of Legitimate Organs through Altruism

The second means through which the anti-transplant abuse campaign has curbed commerce in organ transplantation is by changing the source of organs from *purchase* to *altruism*, largely through shifting from live to deceased donors. As we saw in chapter 3, this shift follows the developmental path of transplantation in the United States, and many other countries. For example, the Declaration of Istanbul permits what it calls “travel for transplantation” but distinguishes it from “transplant tourism.”⁷⁵ “Travel for transplantation” is defined by two practices: 1) *non-involvement* in organ trafficking or transplant commercialism; and, 2) *non-interference* with the host country’s “ability to provide transplant services for its own population” (Participants in the International Summit On Transplant Tourism and Organ Trafficking, 2008: 2). It is the last point in the definition that reveals an underlying commitment to a nationalist organ exchange model.

⁷⁵ The case example is a transplant candidate who travels with their potential donor to a transplant centre in another country because there are no transplant centres in their home country.

This sends a message that organs are best distributed within nation-states, exchanged among a *national* population. Some campaign activists take nationalism a step further by articulating the position that countries should not only “address their responsibilities to protect their people from exploitation,” through transplant tourism but should also “develop national self-sufficiency in organ donation” which overwhelmingly means establishing a deceased donor program (Francis L Delmonico, 2009: 117).

The shift toward legitimate organs has meant investing in healthcare system infrastructure to establish processes that identify potential donors, secure consent, access databases, and that procure and exchange organs from intensive care units to transplant centres within strict timeframes. Changing the source of organ supply in favour of altruism has also required building the community altruism market where it does not exist, starting with legal and cultural acceptance of brain death. For example, the Coalition for Organ Failure Solutions and transplant professionals actively lobby for the acceptance of brain death in a number of countries where deceased donation does not currently occur.

Several countries have taken steps to introduce deceased donor *community altruism*. In 2010, the United Arab Emirates and Egypt passed legislation to permit deceased donation. In 2007, China announced a ban on foreigners receiving transplants (BBC, 2007). That year China also enter into an agreement with the World Medical Association that organs of prisoners must not be used for transplantation except for members of their immediate family (Kilgour & Harvey, 2012). Vice-Minister of Health, Huang Jiefu, was quoted saying, “transplants should not be a privilege for the rich,” while also acknowledging that some hospitals ignored rules because of high profits from the sale of executed prisoners’ organs to foreign patients (Branigan, 2009). In March 2010, the country announced many changes toward a version of *community altruism*. A pilot project was

announced with a view to establish a national voluntary, posthumous organ donation program (Juan, 2011).

However, China's shift away from using executed prisoners as their pool of deceased donors has yet to be proven. Research, lobbying and publications on this issue by Canadians David Matas and David Kilgour led to the formation of a new anti-transplant abuse organization, Doctors Against Forced Organ Harvesting, with the goal to end unethical organ procurement practices in China (www.dafoh.org). According to their research, international organizations including the World Medical Association, United Nations Committees and Rapporteurs, The Transplantation Society, and Declaration of Istanbul Custodian Group have never been able to verify implementation of the announced changes. Disappointment led the The Transplantaion Society to impose an exclusion of their members seeking or accepting professional engagement with Chinese transplant professionals. As a result of continued lobbying by The Transplantation Society and other international organizations, the *Hangzhou Resolution* was signed in 2013 to affirm the commitment to stop using organs from executed prisoners (The Transplantation Society, 2014). But, another media report in December, 2014 announced a new date of January 1, 2015 for ceasing to use executed prisoners (BBC, 2014).

In Canada, a client country, the promotion of community altruism is a common public relations response to media reports of transplant tourism. For example, amid a news flurry of attention on transplant tourism, the President and CEO of the Trillium Gift of Life Network, Ontario's organ and tissue donation agency, wrote in a letter to the editor of the *Globe and Mail* that, "if Canadians find the idea of transplant tourism repugnant, as I hope they would, they can do something about it by registering their wish to be an organ or tissue donor when they die" (Markel, 2010). The statistic cited in the letter was that four out of every ten potential deceased

organ donors are lost because the family does not consent, the message being that pre-registering consent to deceased donation will improve the national organ supply and thereby prevent transplant candidates from heading abroad.⁷⁶ This response thus incorporates the fight against the commerce of organs for transplant into existing practices of exhortation for deceased donation.

7.2.4 Current Challenges to the Anti-Transplant Abuse Campaign

By 2010, the central accomplishment of anti-transplant abuse actors was recognition that commercial markets which violate human rights exist, and, that for that reason, must be stopped. Coalition for Organ Failure Solutions founder Debra Budiani-Subari argues that the effort to combat organ trafficking and commercialism “has come a long way, especially in terms of transparency...you couldn’t even mention organ trafficking a few years ago” (D. Budiani-Subari, personal communication, August 30, 2010). There remain, however, many challenges to the anti-transplant abuse campaign.

The central challenge to curbing the illegal trade in organs using legislation is dependency upon political will and law enforcement as state structures vary widely in commitment and capacity to uphold the law. Transplant surgeries involving organ trafficking, transplant tourism, and transplant commercialism generally occur in low-capital countries. Political will and law enforcement in all jurisdictions, but especially in these locations, is hampered by internal and external pressures to support private enterprise by maintaining a minimal regulatory environment.

⁷⁶ Notably, the *problem* with transplant tourism in such narratives is often recipient-centric: organ recipients may get their transplant but suffer adverse health outcomes (see for example, (CBC, 2011). The ethical consequences of transplant tourism, such as any consideration of responsibility for individuals whose organs are removed, is thus effectively evaded.

Further, in many countries, the underfunding of the public sector results in a structural context that weakens enforcement capacity (Dewey, 2008).

In the absence of strong state-level enforcement, there is debate among medical professionals over the extent to which professional societies, such as The Transplantation Society, can *police* their own members. Societies are not regulatory bodies; like the WHO and the UN, they lack any form of binding authority. They do, however, hold moral suasion, but this is tempered by two factors. First, professional loyalty can work to maintain a code of silence instead of exposing colleagues who are violating standards of ethical conduct. Second, a lack of consensus exists between the leadership and membership over whether a regulated, commercial market has the potential to undermine the anti-commerce campaign. For example, the American Society of Transplant Surgeons expresses support for the Declaration of Istanbul but withholds official endorsement because it also supports “limited trials of measures to provide incentives for organ donation,” and the use of “incentives” may be in conflict with the Declaration (Reed et al., 2009). Finally, at the individual level, some transplant surgeons have publicly refuted the idea of universal human rights, arguing instead that commercial organ sales are culturally appropriate in their context (Ghods, 2008; Sever, 2006).

Further, the anti-transplant abuse campaign does not possess the means to address the structural factors that enable organ sales, including the poverty that most vendors/survivors identify as motivation for their kidney sale. In other words, trafficking is fed by conditions of inequality that contribute to vulnerable populations. For instance, Yea (2010) found that kidney sellers in a Manila slum would be less likely to participate if they had other means of generating income. As such, Yea argues that a development approach would be a more suitable and effective approach to combating the international organ trade.

Similarly, in speaking of barriers to implementing wide scale deceased donor community altruism in his country, Iranian transplant doctor, A. J. Ghods (2008: 78) argues that “many infrastructural deficiencies (along with cultural barriers) prevent large-scale implementation”. With respect to increasing intimate altruism, he argues that this “will surely result in coercion, particularly of female donors,” (Ghods, 2008: 78) which he argues is more unethical than the use of paid living unrelated donors.

New research also points to the existence of a *spectrum* of types of participation in transplant tourism and commercialism. Yea (2010), for example, shows that the experience of commercial kidney providers in Baseco, Manila fits few of the characteristics of trafficking. With the important exception of medical intervention, organ sellers may have more in common with other marginalized workers such as sex trade workers. In the same vein, Scheper-Hughes (2010) argues that kidney sellers require “unions and collective bargaining because as a potential labour force they constitute the poorest, weakest” and that they also need “access to adequate medical insurance for the rest of their lives.”⁷⁷ Notably, the idea of organizing body part donors has a precedent. A 1963 article reports on a “national blood donation movement in India” wherein commercial donors demanded “no profiteering at our cost” (E. Arthur Dreskin, 1963; Titmuss, 1970).⁷⁸

⁷⁷ Notably, Scheper-Hughes is articulating a need, *not* suggesting that postoperative provision of insurance should be offered upon condition of kidney donation. (Not only could insurance easily be considered exchange for “valuable consideration,” but the notion that a kidney becomes the cost of social citizenship is anathema to her position.) Pro-regulated market advocates point to the provision of universal health insurance in arguing that places such as Canada are more ideal for such systems.

⁷⁸ Titmuss referenced Dreskin’s article in a circular called *Transfusion*. The article did not provide any additional details beyond noting the existence of this “movement.”

Existing integration of public and private healthcare in the service of the international market for transplants may also pose challenges to the anti-transplant abuse campaign. For example, in early 2002 transplant tourism was linked to the development of an export market in private healthcare services for foreigners in numerous low-capital countries (Drager & Vieira, 2002). Excluding transplantation from medical tourism would thus require recognizing this therapeutic modality as distinct from other medical services. More problematic still are instances in which the state is a sponsor in the promotion of transplant commercialism. Turner (2009) identified state complicity in the case of the Philippines, where a public-private partnership was struck that promoted medical tourism, including kidney transplant surgery.

Some of the more fundamental positions of the anti-transplant abuse campaign are also challenged in resource-rich countries, especially in the United States, by advocates of a regulated system of cash for organs (Satel & Chapman, 2010). According to such a view, establishing a regulated commercial market for organs is justified on two grounds. First, proponents argue that altruism is a failure, even accusing the prohibition on exchange for “valuable consideration” as “responsible for the injustices of needless deaths by patients awaiting organs” (Cherry, 2005; Goodwin, 2006; Satel, 2008d; Taylor, 2005). Such a position is premised on the idea that a pool of eligible potential living donors exists; they just do not have enough incentive to come forward. This is generally proposed in unequal societies where there is a substantial low-income population. Money in this proposed change in rules to influence donor pools is seen as guaranteed to increase the organ supply. Second, proponents of a regulated commerce system for organs assert that regulation will end the abuses currently observed in the free and prison-based commercial markets. As we see below, it is in the shared target of blame on altruism as a public policy that the pro-regulated market position retains traction.

7.2.5 Blame and Shame in the Stymying of Anti-Transplant Abuse Measures

Overall, lack of direct legislative action against the illegal trade in organs in Canada and elsewhere is easily attributable to the small numbers of transplant tourists, the challenges of enforcement, and competing government priorities. Although very likely an under-estimate, chapter 4 identified twenty-eight Ontarian buyers over the course of a decade. However, there is some evidence to suggest deeper reasons for provincial and federal level inaction that substantiate theories of organized altruism requiring loyalty and stifling critique presented in chapter two.

When news of transplant abuse first emerged there was resistance to investigating or even recognizing nefarious activity. An article published in 2000 by staff of the European OPO Eurotransplant complained that voluntary donations decline following media horror stories about the purchase of organs from living unrelated donors (B. Cohen, Persijn, & Vanrenterghem, 2000). A US Department of State webpage on “Identifying Misinformation” made the same case for silence in stark terms:

Voluntary organ donation is a very altruistic activity, and *one that can be adversely affected by any perception of impropriety or illicit behavior*. Worldwide, there are long waiting lists for organ transplants that exceed donor supply and, as a result, people die every day because of the lack of sufficient donor organs. To the extent that the organ theft rumor has been believed, it has very likely *decreased voluntary organ donation*, and thereby caused many premature deaths (USA Dept of State, 1996).

The accusation that the rumor causes premature death (repeated elsewhere in the same document as causing “an indirect but very real loss of life”) undermines raising legitimate concerns (USA Dept of State, 1996). This stance has two effects. First, silence runs counter to the requirements of transparency and accountability for democracy. Drawing on my interpretation of Godbout and Callié (1998), silence of anything negative may be a ‘cost’ or downside of community altruism.

This further supports the argument made in previous chapters of dominant knowledge and deflection of attention to knowledge (marginalized to caveats) that limit the supply of deceased donor organs. Second, with respect to the actions of recipients who cause harm, as Moniruzzaman demonstrates (see chapter 2), this cost, while unintended, amounts to complicity in transplant abuse.

Second, inaction could also be more explicitly attributed to recipient-centrism, effectively abdicating buyers of responsibility. This follows the logic that buying an organ abroad is justified by the government's failure to provide one within a reasonable timeframe. Even more subtly, as a society, we are not prepared to criminalize ill and desperate patients for whom the discourse of donation exhorts sympathy. Transplant tourists originating from Canada and elsewhere are thus not faulted for their actions.⁷⁹ This is perhaps the best explanation of why in every position statement condemning transplant abuse is a call for countries to increase the legitimate supply of organs, which extends to the call by anti-transplant abuse advocates for countries to become self-sufficient (Francis L. Delmonico, 2011). In other words, fixing the national organ shortage problem comes first, which serves to undermine the adoption of policy measures that would aim to stop transplant abuse.

The blaming of government is further deepened with the embracing of national shame in regards to organ and tissue shortages. For example, the 2012 Canadian Blood Services "Plan of Action" begins with the following dedication on the first page:

Call to Action is dedicated to all Canadians whom the organ and tissue donation and transplantation system has been unable to support, including those who have

⁷⁹ The question of risk of harm from buying organs is more comfortably raised and is more easily substantiated for recipients (rather than providers) because of the ability of transplanters in Canada and elsewhere to study returning recipients who develop postoperative health problems. The unintended impact on the body of knowledge is to exacerbate the imbalanced visibility of recipients compared to the relative invisibility of kidney providers.

died while on transplant waitlists, those who never made it to a waitlist, those who wanted to donate and could not, and those who have had to wait for cornea transplants in some parts of our country *despite an adequate number of potential donors* (Canadian Blood Services, 2012: 2, emphasis added)

This report opens, thus, with an admission of fault. The next line continues by stating that, “outcomes might have been different” were the proposed system already in place. As demonstrated in previous chapters, this narrative of blame and shame perpetuates the dominant claim that “the system” can deliver organs and enough organs. The “system is responsible” position articulated here justifies further investment; it inhibits recognition of the ways in which the problem of organ shortage is a social construction. Further, system blame rests on a denial that there are limits to the extent to which the organ shortage problem is amenable to intervention. Again, this orientation is a move away from recognition of relationality and the recipient-donor tension. With respect to transplant abuse, system blame keeps the focus on consent and hospital efficacy and away from opening up discussion of risk of harm and donor protection; my argument is that this tendency stymies anti-transplant abuse measures.

Blame and shame of deceased donor and community altruism failures was also suggested in interview-based research collected for this study. An interviewee (Tx 1) expressed frustration that Canadian provinces block efforts to capture the number of Canadians engaging in transplant tourism. According to the interviewee, capturing this data is “as simple as tweaking one field” to differentiate between a “legitimate transplant” and “purchased organ” in an “out of country transplant” data entry variable, which is routinely collected at renal transplant centres across the country. His explanation was that “the provinces don't want that information to come out,” and thus stall on the issue.

Further, in interviews conducted with individuals who are directly involved in

transplantation—especially organ donor advocates for TGLN—all interviewees expressed discomfort with and aversion to the topic of transplant tourism. They were of the view that transplant tourism had nothing to do with their campaign to increase community altruism consent to donate in Canada. A few acknowledged that the actions of transplant tourists “made them look bad.” While there was overall condemnation, a few admitted feeling empathy for buyers and having contemplated but ultimately rejecting going this route. The living donors that I interviewed also did not perceive or express any sense of solidarity with commercial donors.⁸⁰

7.3 The Emergence of Living Donor Protection Standards

The second major ethical response to the flourishing of an international, for-profit commerce in kidneys for cash – as well as the use of altruistic unrelated donors and more living donors altogether – is the emergence of protection standards for living donors. As we saw in chapter 4, the number of living donors accelerated significantly throughout the 1990s, increasing for example by 254 percent from 1992 to 2003. Yet the rules – both rigid and pliable – applicable to living donors are minimal: as long as a donor consented and there were no signs of monetary trade, transplant centres in Ontario and similar jurisdictions are free to independently determine the balance of beneficence and non-maleficence. And there remains no institutionalized mechanisms of accountability that would ascertain whether those decisions caused harm or not. As we see below, in the year 2000, transplant professionals came together for the first time to establish

⁸⁰ Further research is warranted on the perceptions and feelings about transplant tourism by direct participants and advocates of organ donation in Ontario to examine the suggestion revealed in this research finding that recipients positioned as immoral agents undermine the collective conceptual position of recipients as “innocent subjects” (Pratt, 1992). In addition, further research is warranted that examines how exhortation for consent to deceased donation necessarily relies—and, moreover, *insists*—on the “innocent subjects” position to compel giving.

medical practice standards to protect living donors. As opposed to lobbying to change laws, this approach is one of encouragement and influence.

By identifying best practices and asserting moral authority as the leadership of the international transplant community, professional organizations have sought to persuade⁸¹ all transplant centres to adopt a standard set of procedures and criteria deemed necessary to safeguard living donors and keep transplantation ethical and legitimate. This means, among other things, recommending the rejection of some potential donors and providing follow-up care. There are many laudable stipulations in the guidelines that, if followed, enhance donor protection. However, as I demonstrate here, though the transplant community has come to recognize the risks involved for living donors, the recipient-centric desire to enable transplantation means that living donors are rarely ruled out entirely. The tension between the interests, again, of donors, intermediaries and recipients casts doubt on whether donor protection can ever really be assured.

I begin this section by providing an overview of early donor protection standards, both in terms of the concerns addressed and fundamental principles asserted. I then introduce the three contemporary donor protection guidelines relevant to Ontario, the discussion of which comprises the remainder of this section. Here I tease out commonalities and differences in regards to a number of donor protection themes and guideline recommendations, including endorsement of a two-team approach for donors and recipients (replicating deceased donation), ethical engagement with donors, informed consent procedures—namely communicating risks, ensuring voluntariness and altruistic motives, as well as psychosocial suitability—and donor financial considerations. I then

⁸¹ Because the international transplant community has no enforcement capacity, the guidelines discussed here only establish parameters to justify use of living donors. As such they follow an *encouragement* approach as opposed to a legal rights or enforcement approach.

proceed by addressing the limits to the implementation of the guidelines. Finally, I conclude the section by reflecting on the tensions between recipient-centrism and donor protection evident both in the external environment to which the guidelines are responding and within the text of the documents themselves.

7.3.1 Early Donor Protection Guidelines

The setting of minimal ethical standards of practice, especially for donor evaluation and selection, officially began in 1985 with a statement by The Transplantation Society called “Commercialization in Transplantation: The Problems and Some Guidelines for Practice.” The principle asserted therein was that transplanters are trusted facilitators of altruism: “The Council of The Transplantation Society takes the view that the donation of an organ is a gift of extraordinary magnitude and that transplant surgeons hold a donated organ in trust for society” (TTS, 1985). Taking into consideration “the ramification for transplantation as a whole,” the Council of The Transplantation Society thus provided guidelines for cadaver organ distribution and for the donation of kidneys by unrelated living donors (TTS, 1985: 715).

The Transplantation Society statement makes several salient points that stand the test of time. First is that transplantation has always been marked by biomedical and social “barriers.” And, further, that social barriers, also known as “ethical doubts,” follow a pathway that either remains contentious or comes to be “still debated” but “generally resolved.” At this juncture then, using living donors had become accepted practice, and the debate of the day was whether to allow for unrelated living donors, especially spouses. Second, the justification for using live donors was established as relying on two primary factors: (1) favourable comparison to the use of deceased donors both in terms of recipient wait time (dependent upon supply) and outcomes; and (2) the

existence of a relationship between donor and recipient. The recommended guidelines for the donation of kidneys by *unrelated* living donors were thus as follows: exceptional use, legal age, meeting the same ethical, medical, and psychiatric criteria used to select related donors, as well as establishing “that the motives of the donor are altruistic and in the best interest of the recipient and not self-serving or for profit” (TTS, 1985).

A decade later, evidence of variation in living donor care was documented in a 1995 survey of renal transplant centres in the United States.⁸² An article based on a survey by the American Society of Transplant Physicians, titled “Evaluation of Living Renal Donors,” reported that inconsistencies in selection criteria and donor evaluation had evolved in different centres since the first live donor in 1954 (Bia et al., 1995). Key findings included that larger centres were less likely to exclude potential donors, that many centres used donors with borderline or mild hypertension, and that compared to a survey conducted in 1986, a more liberal attitude existed toward using donors over fifty-five years of age.

Discussion of these survey findings raised concern about both the quality of donated organs and the implications for recipient health outcomes. With respect to donor health, it was noted that there was “substantial variability among centers in tests used to screen for diabetes and heart disease among donors” (Bia et al., 1995: 326). Further, “while there is little controversy concerning the risk of mortality, there is a greater diversity of opinion about the long-term risk, if any, of End-Stage Renal Disease from renal donation” (Bia et al., 1995: 326). The American Society of Transplant Physicians therefore called for the transplant community to collect long-term follow-up data for all living donors in a national registry in order to analyze the risk of developing kidney

⁸² A parallel survey was conducted concerning potential recipient evaluation.

disease and verify the safety of renal donation. Given that, from 1977 to 1992, 80% of centres had only followed up with renal donors for a few months to a few years (or in the case of complications), there was a paucity of data on the close to 24,000 living donors from which to inform selection criteria of future donors. As the society stated at the time, “until it is clear [...] that this [observed] incidence [of renal disease] is no greater than that expected in the general population, we should continue to collect data on renal donors” (Bia et al., 1995: 326).

7.3.2 Current Donor Protection Guidelines

Beginning in the 2000s, the rise in volume of donors, along with expanded eligibility criteria and use of parts of other organs from living donors, prompted the release of a series of new guidelines called *consensus statements* (Table 17 below). Each of these guidelines emerged from multi-day forums with interdisciplinary experts. The goal of the statements was to provide professionals with ethical, medical, and psychosocial practice standards for evaluating suitable living donors and providing follow-up care.

Table 17 *Consensus Statements on the Care of Living Donors*

Year	Author	Consensus Statement
2000	Live Organ Donor Consensus Group (JAMA)	Consensus Statement on the Live Organ Donor
2004	The Ethics Committee of The Transplantation Society (TTS)	The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor
2005	The Ethics Committee of The Transplantation Society (TTS)	A Report of the Amsterdam Forum on the Care of the Live Kidney Donor: Data and Medical Guidelines
2006	The Canadian Council for Donation and Transplantation (CCDT)	Enhancing Living Donation: A Canadian Forum

The 2000 “Consensus Statement on the Live Organ Donor” published in the *Journal of the American Medical Association* (JAMA)—hereafter the *JAMA guidelines* (as they are referred to

in the field)—marks the first public assertion by transplant professionals that while live organ donation “is ethically acceptable,” donors are patients who must be treated appropriately prior to operation and postoperatively. In other terms, not only does the patient with end-stage organ failure matter, but so too does “the healthy person who volunteers to donate and whose interests are equally important.” The guidelines emerged from a two-day summit with participation from recipients, donors, four sponsoring organizations, and one hundred experts, including physicians, nurses, ethicists, psychologists, lawyers, scientists, and social workers. The stated goal of the JAMA guidelines was to “[ensure] that the welfare of potential and actual donors remains preeminent in the process of live organ donation” (JAMA, 2000: 2919).

In 2004, at what is referred to as the Amsterdam forum, nephrology experts from forty countries, representing every continent, met for four days to establish practice guidelines specific to live kidney donors. This effort was sponsored by The Transplantation Society in alliance with the World Health Organization (WHO). The work of the forum is divided into two documents, but which, for the purposes of this chapter, are collectively referred to as the *Amsterdam guidelines*. The first, “Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor” by The Ethics Committee of The Transplantation Society is a six-point recommendations list for ethical procedures prior to and after live donor nephrectomy. A document released a year later, “Report of the Amsterdam Forum on the Care of the Live Kidney Donor: Data and Medical Guidelines,” provides a complementary set of medical guidelines, including a section discussing live donor organ sources (categories) of living unrelated donors and kidney paired-exchanges.

In 2006, the transplantation committee of the Canadian Council for Donation and Transplantation (CCDT) (2002–2006) held a national forum over four days on living organ donation. Two donors, two recipients, eighty-six experts, and twenty-three organizations

participated in the forum. The CCDT's overall mandate was to increase the number of organs available for potential recipients. Throughout its existence, this organization's initiatives were dominated by a focus on deceased donation. The 2006 forum marks the first and only time that experts have met in Canada to address live organ transplantation. The forum produced a total of eight background papers as well as a report and recommendations document, titled "Enhancing Living Donation: A Canadian Forum," hereafter referred to as the *CCDT guidelines*. While largely repeating the contents of the JAMA and Amsterdam guidelines, language employed in the CCDT guidelines places greater emphasis on "risks" and "barriers."

7.3.3 A Two-Team Approach

At the heart of these guidelines is recognition of a conflict of interest between potential recipients and potential donors who share the same set of medical providers at renal transplant centres. Given that the goal of transplantation is to treat patients with end-stage renal disease, these statements acknowledge that intermediaries hold a bias in favour of transplant candidates—in other words, *their* nephrology patients. The guidelines thus aim to assert donor-protective limits through professional regulation.

In order to ensure voluntariness, all three guidelines recommend what (Rose, 1994) calls a *dividing practice* of a two-team approach. Physicians involved in the care of the potential recipient "are, and ought to be primarily concerned with the recipient's interest" (JAMA, 2000: 2920). Hence, the guidelines urge that there be an independent advocate for the donor "whose only focus is the best interests of the donor" (JAMA, 2000: 2920). Ideally then, transplant providers would

comprise two separate teams—one for the donor, and one for the recipient.⁸³ The JAMA guidelines also note agreeably that the policy at some transplant centres is to not share donor information with the recipient out of respect for patient autonomy and confidentiality. However, in chapter 8, I show how the rules of separateness are strained by timing and communication.

7.3.4 Ethical Process

With slight variations, all three guidelines assert that transplant providers at transplant centres are both responsible for providing appropriate care to donors and for ensuring that the exchange is legitimate and justified. The guidelines weigh heavily on questions of ethical process given that, as stated by the Amsterdam guidelines, the live kidney donor must be regarded as the “responsibility of the community.” While live organ donation is understood as accepted medical practice, voluntary, cost-saving, and a site of “opportunities and challenges,” it must, in the words of the CCDT guidelines, “be undertaken with the highest possible standard of clinical care” (CCDT, 2006: 2). For example, statements asserting that potential donors, as healthy individuals who are not otherwise patients, “become special patients” in the process of testing to determine their eligibility are commonplace in all three guidelines. Action to capitalize on living donor “opportunities” must thus be tempered by ensuring donor protection.

For transplant providers, acting ethically means, first and foremost, following due process both prior to operation and postoperatively. The goal is to ensure that only the right people donate, for the right reasons, and that donors receive adequate follow-up care. While there is variance

⁸³ This practice notably directly parallels the two-team approach in deceased donation whereby intensive care unit physicians—not transplanters—declare death. In both instances, the conflict of interest between donor and recipient resides in their medical providers.

among the three guidelines, the purpose is the same—to offer instructions on *how* to act and provide the terrain of knowledge within which transplanters can seek to ascertain right from wrong. The *how* imperatives of process are similar in all three guidelines, with each reviewing evidence on mortality and morbidity risks of potential donors. The Amsterdam guidelines offer details of medical knowledge pertinent to potential kidney donation through a long list of conditions, general health (including the absence of cancer and infectious disease), and renal function. Thus, the CCDT medical assessment recommendations for kidneys refer clinicians to the Amsterdam guidelines, while also noting the need to seek “higher quality evidence” as it becomes available and “that these guidelines not be used as absolute criteria where risk is poorly quantified or uncertain” (CCDT, 2006: 23).⁸⁴

The JAMA guidelines also note that the final decision to perform the live donor nephrectomy and transplant rests with responsible parties—the transplant team, donor advocate (donor evaluation team), potential donor, and recipient—in their collective determination that the benefits outweigh the risks. In this matter, the responsible parties must be in agreement, and there must be autonomy “that prevents undue pressure on the medical team to perform a procedure that they do not believe is medically indicated” (JAMA, 2000: 2925).⁸⁵ One notable addition found in the Amsterdam guidelines is the statement that “donor autonomy does not overrule medical judgement and decision-making” (TTS, 2004: 492).

In terms of long-term postoperative health, both the CCDT and JAMA guidelines endorse the 1995 call for a national living donor health outcome registry. In the words of the JAMA

⁸⁴ I discuss other central components of donor eligibility in chapter 8.

⁸⁵ This explicit mention of autonomy may be in reference to patient activism and desperation or to pressure stemming from for-profit hospitals seeking to raise revenue via expensive surgeries.

guidelines:

The rationale for the development of such a registry includes concern for donor well-being, limitations of current knowledge regarding the long-term consequences of donation, the potential to evaluate the impact of changes in criteria for donor eligibility on the outcome of donors, and the need within the transplant community to develop mechanisms to provide for quality assurance assessments (JAMA, 2000: 2925).

While the Amsterdam guidelines also recommend the establishment of a registry for “donors considered to be at potential increased risk for adverse events” (TTS, 2004: 492), they also place emphasis on adopting a four-item list detailing the immediate and long-term postoperative responsibility of transplant centres for the wellbeing of live kidney donors. The caveat is that responsibility is limited to “morbidity that is a direct consequence of donor nephrectomy” (TTS, 2004: 492).

Acting ethically is also, notably in the CCDT guidelines, *for* donors but equally *for* recipients and *for* transplant providers as they are ambassadors of professional organizations and institutions that depend on trust:

In the long-term, it is anticipated that this initiative will effect change in systems supporting live organ donation such that the activity can be maximized in a safe and ethical environment *while enhancing confidence* in live organ donation for potential and actual donors, transplant recipients and their families, members of the public and health care professionals (CCDT, 2006: 5).

Similarly for the Amsterdam guidelines, the objective of donor protection through professional regulation is meant to protect both donor health and wellbeing and the international transplant community from the sullyng of their profession:

The international transplant community recognizes that the use of kidneys from the living donor needs to be performed in a manner that will minimize the physical, psychological, and social risk to the individual donor *and does not jeopardize the public trust of the healthcare community* (TTS, 2004: 491, emphasis added).

Fundamentally, guidelines recognize that transplanters mediate between donors and recipients. In doing so, transplanters form their own relationships with each party and have their own interests at stake. One observation of all guidelines reviewed here is that, to a certain extent, donor protection recommendations tend to address the donor-transplanter relationship more than they do the donor-recipient relationship.⁸⁶ This may reflect an underlying priority to ensure that the approval process meets institutional obligations towards donors.

7.3.5 Informed Consent I: Understanding Donor Risks

Criteria related to the informed consent of potential donors are addressed by all three guidelines. As part of informed consent, the JAMA guidelines require that donors understand the risks to themselves, benefits to the recipient, and alternative treatments available to the recipient, such as dialysis. The onus to present this information is placed on medical providers, including a twelve-item list detailing various elements of disclosure during the potential donor assessment process. In this regard, the guidelines state that:

It is incumbent on the transplant center to provide full and accurate disclosure to potential donors of all pertinent information regarding risk and benefit to the donor and recipient. The relationship between the donor and recipient should not alter the level of acceptable risk. A familial relationship does not impose on the donor (or the recipient) the necessity to take on additional medical risk to accomplish donation (JAMA, 2000: 2920).

As a safeguard, the guidelines also note that “the disclosure process should permit a ‘cooling off period’ between consent and the scheduled donor operation to provide the potential donor ample time to reconsider the decision to donate” (JAMA, 2000: 2920).

⁸⁶ While this theme is also touched upon in chapter 8, further research is warranted on the intersections and variations in the mediation despite multiple allegiances of the three primary actors—potential donors, potential recipients, and transplant centre staff.

The disclosure of risk to donors is also central to the Amsterdam guidelines, including informing potential donors of the risk and implications of treatment and future insurability of discovering unknown medical conditions as a result of testing. Risk is, in fact, the rationale of the Amsterdam forum:

Because of the need for more transplantable kidneys, persons with conditions that may increase the health risks for the potential donors and/or recipient (for example, hypertension) are currently being considered as donors. The international transplant community recommends that the acceptance of such individuals as kidney donors be conducted *in an ethical manner*, accounting for the autonomy and safety of the donor and with rigorous attention to clinical outcomes (TTS, 2004: 491 , emphasis added).

Emphasis on risk to donors in the Amsterdam guidelines marks the beginning of a decade of debate within the transplant literature on a category of donors not visible to the public—the “medically complex living donor.” In chapter 8, I discuss the significance of epistemological questions in how Ontario transplant centres negotiate approval or exclusion of potential donors whose medical suitability falls into a grey zone.

7.3.6 Informed Consent II: Voluntariness and Altruism

Another aspect of informed consent for potential donors is that the decision to donate be of a voluntary, altruistic nature. The JAMA guidelines, in this respect, largely continue the spirit of the 1985 The Transplantation Society statement. As such, the guidelines state that “altruism has been the underpinning of live organ donation since its inception” (JAMA, 2000: 2920). In the Amsterdam guidelines, the notion of altruism is also reiterated. “The decision to donate should be voluntary,” which is protected by “the freedom to withdraw from the donation process at any time [and] assurance that medical and individual reasons for not proceeding with donation will remain

confidential” (TTS, 2004: 491-492). It is incumbent upon the institution to ascertain and document the stated altruistic motive of the donor and probe any possibility of coercion such as may be present in a subservient relationship.

Interestingly, the strategy of having two teams—one for the donor, one for the recipient—as discussed above, simultaneously exposes recognition of a conflict between recipient and donor while also claiming to manage it. Theoretically, two teams enable altruism by sustaining the idea that all parties are on the same side in a positive exchange. At the same time, this *dividing practice* of management reveals that there are different interests at stake (Rose, 1994). Further, to better enable potential donors to say “no,” the JAMA guidelines endorse and justify the practice of providing a false “medical alibi.” According to these guidelines, “this option helps facilitate a fundamental component of informed consent, freedom of choice to be a donor or not” (JAMA, 2000: 2921). In gift theory, such an alibi would help ease the “failed gift” problem of disrupted—especially familial—relationships.

A notable addition to the CCDT guidelines—one not addressed in other guidelines—is an explicit reference to the “gift relationship” that exists between donor and recipient. This arises as part of disclosure of potential donor “material risks and benefits” information to the recipient, which breaches the principle of separating donor and recipient care in the two-team approach discussed above. The recommendation is that such information be shared “within the context of the gift relationship” and subject to “donor consent and a case by case balancing of recipient and donor rights” (CCDT, 2006: 34). A footnote elaborates:

All gifts are exchanged within a donor/recipient relationship which varies between ‘intimate’ for family giving to almost negligible for charitable giving. All gifts involve cost to the giver, and hopefully, engender gratitude in the recipient. Living organ donation involves the additional element of possible health risk to the gift-giver, in addition to the material or financial costs.

Mention of this in the CCDT guidelines offers a rare recognition to the effect that (conscientiously) mediating the relationality between donor and recipient can be challenging and complex, a theme to which I return in chapter 8.

7.3.7 Psychosocial Suitability

Determining the psychosocial suitability of all potential donors also contributes to the process of informed consent. Psychosocial evaluations require transplanters to come to know potential donors in order “to rule out inappropriate donors” (CCDT, 2006: 31). This is accomplished by evaluating potential donor stability (psychological, social, and financial), establishing competency to give consent and voluntariness in donating, as well as competence and ability to cope with major surgery in terms of stress, caregiver role reversals, family support, and logistical preparedness for a period of convalescence.

Psychosocial suitability guidelines reveal a form of practice I identified in my earlier research on deceased donors, described in chapter 3, of a “double gaze” whereby practitioners treat the subject as both subject—for themselves—and as objects—for the other (McKay, 2001). As a subject, guidelines recommend, on the one hand, the evaluation of potential donor stability, competency, and preparedness. The objectifying view for live donors, on the other hand, assesses the relationship to the recipient: what is the nature of the relationship? Is the potential donor vulnerable to coercion from the potential recipient? Is the decision to donate consistent with the potential donor’s values? In other words, is this a normal and healthy relationship, with *pure* motives of altruism, no expectation of return, and appropriate expectations of the outcome?

Notably, transplant centre staff are presented throughout all three guidelines as medical

providers that potential donors can trust. They are thus portrayed as not recipient-centric but as protective of donors. Such portrayals are found in provisions that refer to the context of the decision to donate, for example, in recommending that a non-family member should provide translation, if needed, to ensure donors experience “an environment” in which they feel free “to express hesitations, concerns, or health problems” (JAMA, 2000: 2920). And, in the case of undue pressure from a potential recipient or family member, that the psychosocial evaluation “...may serve as an opportunity to help the potential donor gracefully withdraw from an uncomfortable situation” (JAMA, 2000: 2922).

Thoroughness in caring for donors and acting ethically is challenged here, however, by recipient-centric limits to donor protection. Tension within donor evaluation teams at transplant centres is further revealed by the statement that processes of psychosocial evaluation “cannot be too onerous for the donor” (CCDT, 2006: 31). I interpret this to imply a fear that if too thorough, donor evaluations rule donors out which deprives recipients of an organ. In a CCDT background report on psychosocial evaluation, the authors note that while some donors are found unsuitable in the process, they reassure their audience of transplantation colleagues that this is uncommon. The authors of the report then take up a defensive and advocacy position, arguing that psychosocial evaluation is critical to positive donor outcomes. In their words, such evaluations should “continue to move in the direction of comprehensiveness, and that they be viewed as opportunities not so much to rule potential donors out as to enhance individuals’ eventual suitability as donors” (Dew, Switzer, DiMartini, Myaskovsky, & Crowley-Matoka, 2005: 5). First, this suggests that not all donor evaluation team members at transplant centres value psychosocial evaluations. This possibility was also hinted at in my interview with a donor nurse co-ordinator and social worker when one of them noted in passing that, “they do listen to us,” meaning that at their transplant

centre, within the hierarchy of social workers, nurses, physicians and surgeons, they felt that their voices raising psychosocial concerns were heard (DT4). Second, the idea that these evaluations enhance individuals' suitability denies the gatekeeping role of the psychosocial assessment, instead positioning it as a form of mediating and improving "the transplant experience." Thus, while defending the importance of this aspect of donor evaluation, advocates of psychosocial evaluations rely on certain assumptions. Not only are potential donors viewed as honest and trusting enough to disclose their feelings, evaluators assume that they can (and perhaps should) mitigate or manage any recipient-donor tension. By contrast, Sothorn and Dickinson (2011) found that patients feel under pressure to perform as 'good candidates'. Considering also the asymmetrical power relations of individuals and organizations raised by Steiner (2014), the site of interactions between donor evaluators and potential donors is a site in the process of exchange that deserves greater research.

7.3.8 Donor Financial Considerations

All three guidelines also address donor financial considerations. For instance, the JAMA guidelines take the position that "living organ donors should not personally bear any costs associated with donation" and that lost wages should be defrayed (JAMA, 2000: 2925). The JAMA guidelines note the stance of The Transplantation Society on commercialization—"organs and tissues should be freely given without commercial consideration or commercial profit"—but do not explicitly restate the position. Rather, the JAMA guidelines assert that "direct financial compensation [...] remains controversial and illegal in the United States" (JAMA, 2000: 2925). The guidelines go on to explain that consideration of remuneration "is to provide a stimulus for increasing the number of organs available for transplantation," and that although this may be

plausible, there are “no data to dispute or conclude that financial compensation will significantly expand the living donor pool” (JAMA, 2000: 2925). The debate over compensation, clearly represented by both sides at the JAMA forum, is summarized by stating that those opposed to direct monetary compensation object mainly based on fear of exploitation of the poor, risk of dishonesty resulting in disease transmission, and aversion to commodification of the body. Those in favour of compensation “cited the autonomous rights of individuals as the foremost consideration, and they supported the development of regulatory agencies that would oversee organ sales” (JAMA, 2000: 2925).

The CCDT guidelines identify “financial risk” as a key “barrier” inhibiting the potential for more living donors. That “there is a need to reduce the financial risk to the donor and address concerns reported by living donors” (CCDT, 2006: 2) is clearly identified and labelled as a problem for Canada. This is complemented by a key assumption recognizing that “live organ donors do incur non-medical expenses” (CCDT, 2006: 2). Whereas the JAMA and Amsterdam guidelines linked the issue to the debate over “financial compensation,” the CCDT guidelines avoid such language, instead favouring terms such as “risk” and “barrier,” which imply that potential donors are unjustly burdened. Likewise by excluding language around “illegitimate” organ exchanges involving the soliciting, buying, and selling of organs, the effect is to dissociate the implied policy solution—to financially compensate donors for expenses incurred—from what could be perceived as paying donors for their organs.

While “enhancing” living donation at home is the focus of the CCDT guidelines, evidence published the same year by authors in attendance at the forum recognizes that, as detailed in chapter 4, twenty-eight Ontarians had purchased kidneys from twenty-eight sellers outside Canadian jurisdiction. While the guidelines twice note that the consent process “must comply with

provincial law and regulations” (CCDT, 2006: 35), it is not until four years later that Canadian transplanters address the topic of Canadian transplant tourism (John S. Gill et al., 2010). As I discuss in chapter 8, not only are Ontarians (and Canadians) buying kidneys abroad, buying and selling of kidneys was suspected in a few cases between a potential donor and potential recipient seeking their surgeries in Ontario, at the large renal transplant centre included in this study.

7.3.9 Challenges in Implementation

The main implementation challenge for all three guidelines is that they are unenforceable. In the Canadian case, a mechanism for public assessment of the extent to which any or all the guidelines’ recommendations have been adopted was not established. Obtaining information on implementation is further complicated by the fact that the CCDT has ceased to exist and has been replaced by Canadian Blood Services (CBS) with a mandate that places emphasis on organ (and tissue) acquisition. It does not monitor transplant centre activity. Trillium Gift of Life Network remains focussed on deceased donation and, as we saw earlier, the statistics reported by the Canadian Organ Replacement Register are selective. None of these organizations are independent of transplanters and therefore none are poised to act as an independent monitoring body to serve the interests of potential donors. The Amsterdam guidelines identify the WHO as the organization “to implement these standards” and for participants in the forum to serve as “emissaries” of the standards in their part of the world (TTS, 2005). Transplant centres are autonomous and do not publish information that would allow for public monitoring and, more importantly, potential donor decision-making, such as donor nephrectomy outcome data or differences in donor eligibility criteria.

Overall, guidelines have no force of persuasion other than reputation, which is largely

contained within the profession and within national and specialist circles. Transplant centres have autonomy, as do medical professionals, albeit within constraints of national professional regulatory bodies and government regulation. A background document prepared for the CCDT illustrates this point: among eighteen of thirty-five programs that responded to a survey (for all organs), inconsistencies were found in both medical contraindications and information provided to potential donors about the medical and financial risks of living donation (Cockfield, 2006). In addition, only a minority of programs assumed responsibility for donor follow-up beyond a few months post-operatively, and some programs lacked the financial resources for staffing a dedicated living donor coordinator. A lack of “solid outcome data” for donor hypertension is cited as the reason for the variability in practice between renal transplant centres (Cockfield, 2006: 6). This further illustrates the limits of standard guidelines – they can only be as good as the existing evidence.

7.3.10 Negotiating Between Recipient-Centrism and Donor Protection

Tensions between recipient-centrism and donor protection reside both in the external environment to which donor protection guidelines are responding, while also being evident within the text of the documents themselves. As argued earlier in the dissertation, the discourse of donation used to exhort consent and investment in community altruism deflects attention from donors on the one hand, while also obscuring the relationality of donors to recipients—specifically knowledge that would limit the supply of organs—on the other. Live kidney donation thus shares some of the same characteristics as deceased donation. Most significantly, there is a shared focus on the transplant recipient—in other words, living kidney donation is also, in many ways, recipient-centric. However, what we learn from the CCDT guidelines in particular is that the Canadian transplant community recognizes the shift of the recipient-gaze toward live donors as well as the risks

involved for donors: “The widening gap between supply and demand is putting increased pressure on the use of live organ donors without the adequate data on outcomes of live donation” (CCDT, 2006: 12).

Evidence of the striation of the dominant imperative for obtaining more organs can be found in comparing deceased donor and living donor strategies. First, with public attention continuously drawn to the need for organs for transplant candidates, there is an overall deflection *from the public* of what inhibits living donation—*iatrogenesis*, or harm from medicine. However, as seen in this chapter, the deflection of *iatrogenesis from potential live donors* is less complete. The discourse of donation thus eases in the assertion of limits for live donation, something not seen in deceased donation. Living donor nephrectomy is understood as not merely a gift but as a sacrifice that carries risk to one’s health. It is the degree of risk, and defining harm, that are subject to different interpretations.

Second, living donor organ acquisition strategies are more constrained than for deceased donation. There is no call, for example, for “awareness and education of the opportunity to give,” which is a mainstay of every deceased donor report. The presumption that enough kidneys are “out there,” which sustains and justifies investment in deceased donation is largely replaced by the justification that living donation works better. While there is an effort to keep the focus steadfastly on individual motivation to donate, the availability and alienability of kidneys from living donors is less taken for granted. Government efforts to expand living donation is tempered by the inappropriateness of soliciting for specific individuals as well as the risk of harm to donors.

Negotiating the road between recipient-centrism and donor protection—especially in light of pressures to increase the number of organs, including from medically complex donors—is best described as a search for openings in the boundary around protection to donors. The move to

standardize knowledge of “bioavailability,” as Cohen (2005) calls it, comes in response to its ethical breach, as well as from the desire to push donor protective limits. This latter point is illustrated in the forward to the CCDT guidelines in noting that “[...] there are issues such as the increasing number of individuals with additional risk factors being considered as kidney donors [...]” (CCDT, 2006: 2). Once identified, these openings are labelled *barriers*, which are thereafter seen as surmountable without breaching the ethical wall. This interpretation is perhaps best captured in the stated purpose of the CCDT forum itself: “[...] to build national agreement on strategies to maximize living organ donation while ensuring a safe and ethical environment for this activity, and to overcome the barriers that are current disincentives to live organ donation in Canada” (CCDT, 2006: 11).

7.4 Conclusion

This chapter focused on the emergence of ethical supply strategies for living donors as well as the resistance to the growth of the commercial mode of exchange for living unrelated organ donation at both the international and Canadian levels. In the first part of the chapter, I discussed how the anti-transplant abuse campaign has led to increasing criminalization of the commerce mode of exchange for organs, while more countries legalize brain death and move toward community altruism. I outlined how through the promotion of a *legitimate* supply of organs, the campaign attempts to channel supply away from *illegitimate* organs. Here I also addressed the main challenges to curbing the illegal trade in organs in terms of legislation, structural poverty, and logistical barriers to deceased donor community altruism. I concluded this section by reflecting on how discourses of blame and shame, which focus efforts on fixing the national organ shortage first, in the end work to stymie anti-transplant abuse measures.

In the second part of the chapter, I detailed the rise of donor protection standards within the medical transplantation community, which seeks to establish ethical, medical, and psychosocial practice standards for evaluating suitable living donors and providing follow-up care. Here I discussed that while laudable on many fronts, the guidelines reveal a nexus of tension between recipient and donor, especially given the acknowledgement of pressures to increase the living donor organ supply. I argued that central to the negotiation between recipient-centrism and donor protection is a search for openings in the boundaries set out to protect live donors.

In Chapter 8, I turn to a discussion of the on-the-ground realities of live donor policies and practices at three Ontario renal transplant centres. I argue that what is considered ethical is a line carved between the recipient-centric/donor-protective tension, enacted most visibly in potential donor evaluation procedures and through making living donor altruism more flexible.

Chapter 8 Constituting Altruism—Living Donor Kidney Exchange On-the-Ground in Ontario

In this chapter I turn to provincial policies and practices for live donation at Ontario renal transplant centres. The analysis that follows responds to Kierans' (2011) and others' call for empirical evidence of the ways in which forms of exchange are constituted in practice. The argument in this chapter builds on the previous one by showing the linkages from the international and supranational levels to the local level in directing a path for what Ontario public policy and renal transplant centres uphold as “ethical” – meaning within the boundaries established by *Gift Act* legislation identified in chapter 3. As I argue here, what is considered ethical is a line carved between the recipient-centric/donor-protective tension, enacted most visibly in potential donor evaluation through techniques of procedure but also by pushing the rules of altruism and alienability to make living donation more flexible. The pool of potential living donors is expanded, and some of the means for converting potential to actual donors are relaxed.

I begin the chapter by identifying how the on-the-ground *ethical practices* of transplant centres in Ontario rest substantially on adherence to most, if not all, ethical guidelines reviewed in Chapter 7. Using data⁸⁷ from eight interviews I conducted with donor team health professionals, I determine that while a cautious approach to donor evaluations exists, challenges and complexities still persist. Difficult cases push staff to come to know potential donors enough – as individuals and in relation to potential recipients, – on psychosocial and medical grounds to comfortably

⁸⁷ The data I draw on in this chapter are limited. While there is sufficient evidence to demonstrate my argument, my findings should be read with caution as suggestive more than decisive. As discussed in chapter 2 (Methodology), primary data for this chapter includes eight interviews with donor team health professionals at three transplant centres in Ontario. Donor teams consist, at minimum, of a donor coordinator who is a registered nurse, a donor social worker, and a donor nephrologist. All interviewees are anonymized as “DT” for donor team and numbered. Interview data are complemented by textual sources related specifically to live donation public policy, as well as hospital specific policies, protocols, operating procedures, as well as a donor manual and ethics guideline.

recommend that donation will strike a balance between beneficence and non-maleficence. This includes managing aggressive recipient-centrism among potential donors and recipients, and the constraints of the medical evidence base. I then turn to a discussion surrounding recent changes in living donor eligibility criteria in Ontario. Four changes are identified, three of which entail increasing donor eligibility through the extending or bending of altruism, while I interpret the fourth change as a narrowing of the gift of kidney donation. Finally, I conclude the chapter by addressing how, while more living donors are made eligible, many remain invisible, particularly medically complex donors and living donors who experience adverse outcomes.

8.1 The Science and Art of Donor Evaluation

Ontario transplanters pride themselves in their institutions, which they describe as “ethical transplant centres.” This study found that live donor evaluation teams generally adhered to international and Canadian guidelines—though these guidelines are unenforceable, and therefore rely entirely on voluntary adherence. Donor evaluation protocols were thus marked by a cautious approach. Compared to simplistic portrayals in media and in public policy, the mediation of kidney exchanges for live donation at these renal transplant centres was acknowledged to be a complex affair in many—but not all—cases. Potential living donors must be healthy and at times the predicted medical outcome for them fell in to a “grey zone” where the evidence base is weak. Staff also had to ensure the law was upheld that no money changed hands between donors and recipients and that coercion or undue pressure to donate were not at play.

In this section, I discuss my research findings as to the on-the-ground realities of donor evaluation processes at three renal transplant centres in Ontario. I begin by outlining pre-screening procedures for potential donors, which is followed by an overview of how the informed consent

of potential donors was ensured in all three centres. Next, I detail how donors and recipients alike were protected from the pressure to donate. I proceed by presenting findings on how the mediation of the recipient-donor relationship was handled in cases of donor withdrawal. I then review both psychosocial and medical suitability evaluation procedures. I also discuss the tension between strict adherence to documentation protocols and a more intuitive, case-by-case methodology as expressed by interviewees. Finally, I conclude the section by addressing issues of complexity in potential donor evaluation as well as the limits to ethical action on the part of transplant team members.

8.1.1 Pre-Screening Potential Donors

Potential kidney donor evaluations in Ontario were found to entail at least seven medical tests—some of which are invasive—and psychosocial assessments over an average period of six months. Because formal evaluation of potential kidney donors is considered resource-intensive, transplant centres were found to work in phases, relying on interviews that pre-screened potential donors before proceeding with testing. Prospective donors must be eighteen years of age or older. They must also provide contact information and proof of blood type, have no absolute medical counter-indications, and sign an agreement to commence a workup evaluation.⁸⁸ A patient education manual is then sent to each prospective donor, and some respond with a clear decision to proceed.⁸⁹

⁸⁸ Such pre-screening helps to quickly rule out individuals which one interviewee categorized as “telephone booth people”—for example, a man searching for redemption after having abused his wife, or a woman seeking to sell her kidney for money to pay for a child’s medical care in China.

⁸⁹ Donor nurse coordinators often receive calls that do not proceed beyond initial inquiry. In addition, many potential donors wax and wane in their interest and availability to undergo and complete a donor evaluation process.

The next step in the evaluation was consideration of the donor-recipient relationship in both biomedical and social terms. In other words, do their *bodies match*? And what is the nature of their relationship? As shown in chapter four, the vast majority of potential donors are “related” to the intended recipient, either biologically or non-biologically. Given that only 10% of all patients on dialysis qualify for a transplant, the intended recipient must therefore be eligible before a potential donor evaluation proceeds. In some cases, health status fluctuations of the end-stage renal disease patient stalled the progress of potential donor evaluation.

8.1.2 Ensuring Informed Consent

Ensuring that potential donors could provide informed consent was a further step in donor evaluation. One technique employed was the assessment of a potential donor’s knowledge by team members. At one centre, this entailed rating potential donors on a scale that represented either a low, medium, or high level of understanding for twenty items of information/education. On this point, a key interviewee reported that, “sometimes it’s very clear. We just say, this is not a good idea. You’re just not an acceptable candidate for kidney donation” (DT1). Assessing the level of knowledge was found to be critical especially, “in cases where there may be some risk. We just have to define that risk to the individual; make sure they understand that risk” (DT1).

However, determining whether a potential donor understands the risks or not was identified as a challenge. Interviewees noted that statistics and numbers were not always the most meaningful tool of communication:

Medicine is all about communication. We can quote statistics; it is not so easy to be sure someone understands statistics. Saying a mortality rate is “3 out of every 10,000 surgeries” or “.03%”—some people are able to grasp that...um, so we have to do it carefully and, you know, there are different ways to describe risk.

Sometimes you have to bring it down to “high risk,” “low risk”...numbers may not be meaningful (DT1).

Establishing informed consent was considered especially difficult when the potential donor’s motivation was high, which was often the case:

That can be tricky because, as I said, these individuals are motivated and they are willing, at the time, to accept anything, any kind of risk to help their loved one, you know, out of a difficult situation. So, that’s where we have to have other members of the team evaluate the motivation. And we actually have psychiatry evaluate all of our potential donors to determine whether there’s any underlying psychological or psychiatric issue that may be clouding the decision-making process (DT1).

Overall, extra requirements and supplementary use of staff time signalled a cautious response to high motivation cases among potential donors. In terms of applied practice, one transplant centre explicitly identified that their healthcare team members “act as moral agents” (University Health Network, 2008: 2).

8.1.3 Providing Protection from the Pressure to Donate

A theme that emerged from the interviews was that of dealing with pressure from highly motivated, emotionally-driven potential donors, on the one hand, and, desperate potential recipients, on the other hand. Psychosocial evaluations (discussed in more detail below) endeavoured to identify pressures on potential donors, most often from the transplant candidate or from their family members. Staff in the renal transplant centres also worked to protect recipients by rejecting prospective donors who might seek reciprocation.⁹⁰

⁹⁰ A report by the Québec Commission de l’éthique de la science et de la technologie (Duquet & Boucher, 2006) notes the risk of blackmail and expectation of future return, for example a donor asking the recipient for help down the road paying their mortgage.

Adhering to guidelines discussed in Chapter 7, the Ontario transplant centres included in this study moved, over time, from providing donors with “independent advice” to providing two entirely separate healthcare teams—one for the transplant candidate and one for the potential donor—in order to minimize recipient-donor related challenges and pressures. One research participant explained that prior to the rise in living donation in the 1990s, “we used to do it all. You’d see the donor, you’d see the recipient. And be doing the two workups together. And often times, some families, they’d be really enmeshed families where you’d have difficulties with communication and trying to keep them separate” (DT4). Similarly, a donor team member at another centre said,

...I don’t think that decision to create teams was based on volume, it was based on need. The ethics of it and really protecting each patient, the recipient and donor separately, advocating, because in transplantation there are many instances of—often it involves families, or people who are not related but in some capacity friends, etc.—so you can have all kinds of issues about coercion and conflict and guilt. And if you have one team looking after both parties, the messages can get mixed in such a way that one of the individuals—often the donor—will feel a certain amount of pressure to go ahead with something he or she may not really feel is in their best interest. So, by separating out those issues, you have a team that is advocating. In other words, the donor team really does everything to make sure that this is a safe, the surgery is safe, and in the best interest of the donor (DT1).

Another protective measure was the establishment of a rule that prospective donors must themselves initiate contact with the donor nurse coordinator. In other words, Ontario transplant centres do not engage in any public or personal solicitation on behalf of their program or on behalf of a transplant candidate. One-on-one education during in-person medical appointments is the standard method of informing potential donors and their family about the option of living kidney donation. One living donor education manual includes a section titled, “Deciding to donate,” which states:

Kidney donation is a sacrifice. It involves surgery that is not needed for your overall health. It is natural to have some concerns about becoming a kidney donor. Here are some reasons that donation may not be right for you:

- Lack of resources to take time off work for evaluations, surgery and recovery
- Responsibilities like young children, elderly parents, work
- Lack of family support
- Feeling pressure to donate
- Expecting payment

If you choose not to donate, do not forget that living kidney donation is voluntary. The fact that you took the time to learn about the process of living donation and carefully consider it is commendable. The donor team will support you in your decision. We will help you to communicate your decision to the potential recipient (The Ottawa Hospital, 2009: 21)

Finally, in all three Ontario renal transplant centres, the privacy and confidentiality of potential donors was also ensured. As such, the living donor team does not disclose information about their evaluation without their permission, and as noted throughout their publications potential donors “are advised that they may withdraw their offer to donate at any time” (Connelly, 2013: 70).

8.1.4 Protecting Transplant Programs

In addition to measures designed to protect potential donors and/or recipients, my research found that staff at Ontario renal transplant centres also attempted to protect *themselves* from being harassed or overburdened by aggressive transplant candidates during donor evaluation processes. More importantly, such measures also served to shield transplant programs from culpability in mediating a medical procedure and the donor-recipient relationship, both of which could potentially cause more harm than good.

In instances where the donor avoids telling their transplant candidate that they no longer want to donate, transplant teams are often caught in the middle of an uneasy donor-transplant relationship. Such an example points to what I term *awkward gift relations*—in other words, potential donors do not want to be seen as unwilling to give. One donor coordinator reported “being burned” and scapegoated in this regard when a transplant candidate called to inquire about the status of their potential donor: “the donor will tell the recipient, ‘Oh, I’ve called and left her all kinds of messages and she hasn’t called me back.’ Meanwhile I’ve never had a call from that individual” (DT4). Such behaviour was, according to the same donor coordinator, rather common. She went on to explain that she “was having a lot of really abusive calls from recipients” (DT4). In an attempt to avoid the unpleasant and unfair nature of these interactions, the transplant team at this centre changed their practices and instituted a rule whereby transplant candidates must consent to not call the donor coordinator. Thus, when transplant candidates call, they are redirected to an equivalent contact person on the recipient team. If they somehow still manage to reach the donor coordinator, they are given a pat answer: “I say, ‘I’m happy to speak with anyone who contacts me on your behalf’” instead of giving them any details as to whether any potential donors have called seeking to donate to them and what the progress of their evaluation (DT4).

Donor teams interviewed for this study also ceased providing medical alibis for donors who withdrew from the evaluation process. According to interviewees, false medical excuses had resulted in potential recipients misdirecting their anger toward the donor team. As such, medical alibis “just didn’t work. It’s really bad practice” that led to “getting burned a couple times from bad examples” (DT 4). However, donor teams found that expanding the definition of what was considered a “medical out” was the solution to donor withdrawal in “extreme situations”:

I think in extreme situations, what we tell them in terms of a medical out, is that this is causing you so much psychological distress that you are not psychologically fit to donate. And that that's a medical reason for you not to donate (DT4).

This donor team felt that this was a defensible stance because

[...] you don't want to increase psychological harm. There is psychological risk if the recipient has a poor outcome. And, those are, you know, things that—you know, people have to be prepared for that and psychologically be prepared for that. But not to the extent where they're so distressed because they've got so much other stuff going on in the background, then it's not a good time for them to donate.

8.1.5 Negotiating Psychosocial Suitability

At the Ontario renal transplant centres included in this study, potential donors were obligated to go through at minimum, one psychosocial evaluation session with the living donor team social worker and one mixed physical/psychosocial session with the nurse living donor coordinator. As discussed in Chapter 7, these sessions cover various aspects of informed consent—including disclosure, capacity, and cognition of risk—while also assessing the social support and mental health of potential donors. Techniques employed in order to obtain this information ranged from different forms of data collection—from qualitative interviews to psychosocial tools—to the verification of information between staff members and intentional time lags between meetings.

The living donor team social worker is primarily responsible for uncovering the “donor’s story.” As such, the social worker asks about the potential donor’s relationship with the recipient, including details about the nature and length of the relationship. Donor team members also look for signs of ambivalence, pressure, or coercion. Donors must have “appropriate motivation” which is “other-oriented” – as required by altruism – but not too much so.

However, as reported in the interviews, the extent of there being *emotion* between a potential donor and potential recipient is not always easy to discern. Donor coordinators acknowledged that there can be a “blurring of the lines” when the relationship between a potential donor and potential recipient falls somewhere between that of strangers and new friends or “undefined kin.” This particular challenge was said to arise at the large transplant centre included in the study in cases involving individuals who fall somewhere between emotionally-related and publicly solicited donors. For example, transplant candidates and members of their family would tell the transplant centre that they were going back to their country of origin to announce to extended family or even to an entire community that they needed a kidney. Then, when a potential donor would come forward, the transplant team was told that he or she is a member of the recipient’s community and therefore emotionally-related. However, as donor team members noted, these individuals could just as easily be categorized as publicly solicited donors. Notably country-of-origin cases were no different in this regard than potential recipients whose need for a kidney was announced at an Ontario church, mosque, or through social media, to a broader community. In all of these cases, it appears that donor teams at Ontario renal transplant centres occasionally find themselves at the front lines of a utilitarian—and possibly commercial—mode of exchange for organs.

Donor team members respond to in-between cases through attempts to gain the trust of potential donors. To this end, they insisted upon full disclosure and honest replies to questions asked, permission to access health records, and other information that may be pertinent to the evaluation:

Um, but with these solicited donors. Um directed donors. We’ve had, you know, a couple of situations where they’ve contacted more than one transplant program to donate to two different individuals. I remember a case where we had a woman who came forward to donate to a specific individual and they didn’t make it known to us at the outset that this was a solicited directed donor. And, uh, we

ended up going ahead with the evaluation, booking the blood tests for compatibility for the cross match. And the lab that does the testing for our program and another transplant centre phoned us and said, “why are you doing a cross match for this lady? We did one for this recipient at the other transplant centre.” So she didn’t disclose certain things to us. We have a lot of that. And some people don’t disclose the fact that maybe they’re on anti-hypertensive medication. Um, they don’t disclose about their health history, whether it be psychological or physical. Or we’ll have certain patients that will let us have full access to records from their family doctor but maybe not from the pain clinic which they’ve visited in the past (DT5).

In Ontario renal transplant centres, discovery of undisclosed information can mean automatic rejection of the potential donor: “That’s a big ‘red flag.’ Then they are declined” (DT4). Sometimes such undisclosed information would come as a result of contacting family physicians who would inform the donor team of a counter-indicated condition. On this note, an interviewee remarked, “[potential donors] are not thinking it through that we’re not going to get this information” (DT4).

Overall, the psychosocial dimension of suitability is both individual and relational. What the data reveal is that individual considerations blend into relational considerations as donor team members probe the health of both the potential donor as a person and the relationship between potential donor and potential recipient.

8.1.6 Negotiating Medical Suitability

Determining the medical suitability of potential donors is in many cases a straightforward process. There are absolute counter-indications to donor nephrectomy—such as diagnoses of diabetes or high blood pressure—the most obvious of which are used to screen out prospective donors upon initial contact. Less clear, however, are cases that fall into so-called “grey areas.” According to a donor team nephrologist interviewed for this study, international guidelines are helpful in identifying set criteria for medical suitability but as it is a relatively young field, the state of the

evidence for medical (and social) outcomes of donor nephrectomy is considered low. He stated that, “in some cases the literature is not very well developed in this area to really guide us” (DT1). Kidney stones, for example, are confirmed in medical guideline documents as a “red flag” condition that is potentially, but not necessarily, an exclusion criterion. In such cases, guidelines call for more specific investigation and predictive judgment.

In the same fashion, my research found that the technique employed for managing challenging medical cases was team decision-making and informed consent. As explained by the same donor team nephrologist,

And, so, each program will define their position on these grey areas. What we do is...have meetings to talk about each case and go back to the donor to discuss the risks with respect to some of these grey zones. And, occasionally, the answer is “yes, we will go ahead,” if the person understands and accepts the risks. If the surgeon is happy to go ahead (DT1).

Such a case arose for Eleanor, who was interviewed for this study and was a recipient of her sister’s kidney. At the last minute the dual surgeries were postponed upon discovery that the sister’s renal anatomy was unusual. After studying her case for three months, the medical team decided that they could proceed. A different renal transplant centre had a “two out of three” rule: tests would be repeated three times, and if two out of the three test results were negative, potential donors were deemed ineligible. At both centres, donors rejected on medical grounds were, however, supported in seeking a second opinion at another transplant centre in Ontario.

Transplant centre autonomy thus plays a significant role in dealing with less clear medical cases. “Grey area” cases point not only to the challenge of determining how much knowledge is sufficient, but also to how uncertainty is managed by melding donor protection with transplant centre protection in the shifting/sharing of the onus of risk with the potential donor—and, sometimes the potential recipient.

The salient point is that Ontario donor teams negotiate medical uncertainty not unlike other areas of medicine, except with the significant difference of performing a surgery on a person who will not benefit and whose health may in fact be harmed by the procedure. Living donors in Ontario whose health status falls into a “grey area” are either turned away, bow out, or, if they are highly motivated, try another transplant centre and accept a higher degree of risk.

8.1.7 Documentation Protocols VS. Case by Case Evaluation

Throughout various stages of potential donor evaluation, patient information/education manuals as well as internal policies, protocols, and procedure forms were produced to both help guide staff members and document each stage of the evaluation process. These policies, protocols, and forms drew on donor centre experience while also referencing the burgeoning academic literature on donor evaluation.⁹¹ Reflecting the development of donor protection in consensus guidelines discussed in Chapter 7, the list of items that centres are required to disclose as part of informed consent has grown over time. This finding is consistent with Timmermans and Berg (2003), who, in the context of an oncology protocol, concluded that donor evaluation protocols, in general, are replete with warnings and place heavy emphasis on informed consent.

Protocols were developed for each category of donor, yet, donor team members repeatedly stated that in practice they proceeded on case-by-case bases. While the vast majority of cases fall into the category of related donors, each case was said to carry its own nuances and required special care and attention. Overall, strict adherence to internal policies and protocols was thus thought to

⁹¹ Over the course of the 2000s, donor evaluation has become a field in and of itself, drawing on numerous disciplines that mirror donor team members in the field of medicine, nursing, social work, psychology, and bioethics.

be untenable, and lessons learned from challenges that arose with donors led to the periodic updating of these documents as well as patient information/education manuals.

The centres aimed to ground their decision-making evaluation practices on social and medical research, but interviewees also spoke of the *art* of arriving at recommendations to approve or reject potential donors. For instance, while procedural documentation is used as evidence to support donor acceptance or rejection decisions made at monthly team meetings, in interviews with potential donors, donor team members watched for other clues such as “red flags,” discussed above, and said they also relied on intuition in their assessments.

A strong sense of responsibility to ensure that only the *right* people donate a kidney was consistently expressed in both donor evaluation processes and interviews conducted for this research. Professional norms of practice and an ethic to do no harm guided team members—or at least ensured that the benefit outweighed any potential harm. For living kidney donation, there was explicit mention of the additional weight to not breach the Hippocratic Oath and of mediating the social relations between donor and recipient. As such, this study confirms the finding of sociologists Fox and Swazey (1978), who argued, decades ago, that in approving living donors, transplant centres act as gatekeepers.

8.1.8 The Complexity and Challenges of Acting Ethically

Complexity arose as a theme in several interviews related to living donation and the donor evaluation process. Instances of strain in the ability to act ethically emerge generally as a result of the inherent tension between the interests of potential recipients and potential donors, even when acting in concert towards a mutually agreed upon kidney exchange. Several of these instances

challenge acting ethically because the donor cannot be central; they are necessarily recipient-centric moments.

Both potential recipients and donors are fully dependent upon the psychosocial and medical evaluations that establish their eligibility for transplantation and donation. They are at one and the same transplant centre trusting the reliability of tests, knowledge and unbiased staff to discover and disclose sufficient information for them to base their consent. For potential recipients to act ethically, they need to trust in the donor evaluation process. Just as there is no formal external information available (such as potential donor approval and rejection statistics and disclosure of adverse events), if and when there is an unpredicted outcome, there is little to no recourse.

Only recently and for the first time, an academic journal published an issue devoted to living organ donor narratives (Rudow, 2012). Public access to these voices is limited, however, to university affiliated people who can access academic journals. One website, called “Living Donors are People Too,” does give voice to the vulnerability of potential donors and offers a critical perspective that challenges the claim of neutrality asserted by transplant centres (C. Wright, 2014).

For donor team members, where the recipient-donor line should be placed was not always easy to discern. At two centres, family coercion was raised as an issue. Donor team members sensed that a potential donor was “under pressure to do it” (DT2). One donor team nurse noted that the psychiatrist had not approved some people. Discussion of team decision-making for final approval or rejection of potential donors also indicated that acting ethically in one’s professional capacity did not necessarily equate with what each team member would consider acting ethically as a team. A passing remark by a donor team nurse regarding team dynamics that “they do listen to us” signaled an internal decision-making hierarchy (DT4). As we saw in chapter 2 and which

warrants further research, social relations within intermediary institutions are, for Steiner (2014), highly relevant to understanding organized altruism.

Where to set limits on the desire to donate by potential donors was also a challenge at times. As we have seen, some potential donors are very determined. In other cases, it is not always clear how to balance ways of seeing potential donors, as individual, embodied persons who are also part of relationships. Clear angst was expressed in at least one interview by a donor team nephrologist who struggled with balancing the short-term versus long-term, and individual versus individual-in-a-couple, interests of a potential donor in the “grey area” of medical eligibility. Approving this potential donor could mean that as an individual, she may suffer long after her spouse, the recipient, eventually dies. Not approving her could deny her one chance of a more satisfying quality of life in the short-term as an individual within a relationship of marriage whose quality depended on the improved health of her spouse (DT1). Seeing the relationality between donors and recipients in intimate altruism – by contrast to community altruism – carries the potential of decision-making far more complex.

Also, two aspects of donor protection appeared to be strained, at minimum, in two instances: with respect to timing and communication. Efforts were made to accommodate the donor’s preference in terms of scheduling donor evaluation tests and, once approved, the date of surgery. Donor evaluations had to wait, however, for potential recipients to be ready. The intended recipient had to qualify for transplantation and maintain this status which was sometimes lost while a potential donor was proceeding through the evaluation process (due to co-morbidities or medical incidents such as a stroke).

With respect to communication, maintaining strict adherence to separate files that could not be viewed by the other team, in adherence to the two team approach of a donor team and

transplant team, was also strained at times. This was the case when the quality of the organ was less than ideal and might cause the recipient health problems. An exchange could be approved, in some cases, only if the intended recipient agreed to post-transplant treatment for a virus, for example. Attaining this clearance necessitates disclosing the donor's health information to the recipient's team in spite of the policy of maintaining privacy and confidentiality. As noted in chapter 7, this type of breach of the two team rule is acknowledged and addressed in the CCDT guideline which recommends that information of "material risks and benefits" be disclosed to the recipient, "within the context of the gift relationship" and subject to "donor consent and a case by case balancing of recipient and donor rights" (CCDT, 2006 :34). As one donor team nurse put it, "in reality, these people know each other and are talking" (DT2). Either way, there are a number of permutations between the seriousness of health information and nature of potential donor-recipient relationships that can challenge transplant centre staff ability to act ethically.

A final issue about acting ethically is to note that what constitutes "ethics" in provincial policy and the ability to act ethically at transplant centres warrants further research. Bioethicists, often the same two to three individuals, tend to consistently "represent ethics" in the development of transplant policy in Ontario and Canada. Hospital bioethicists are consulted by transplant centre staff when confronted by challenges cases. The closed circle of the transplant world does not lend itself to external accountability and critique. Also, it is not clear whether in practice social workers and nurses consider a range of ways in which forms of domination may manifest. For example, broad conceptions of 'kin' may reflect cultural diversity but it may also reflect "fictive kin" relationships created in order to exploit the weaker members of a community (Crowley-Matoka & Lock, 2006).

8.2 Upholding, Extending, and Bending Altruism

Ethical strategies to increase the supply of legitimate organs in Ontario have also led to the broadening of living donor eligibility criteria. In this section, I review changes to living donation eligibility criteria in Ontario by donor subtype, focusing on how altruism as a concept has been upheld, extended, and bent in order to increase the likelihood of kidney donation. As discussed here, the motives of love and charity, as well as the logic of swapping dyads in paired exchange, are widely interpreted by the transplant community as extensions of altruism. What the broadening of donor eligibility criteria reflect, however, is an expansion of the pool of potential donors. This is done, as it was in deceased donation: almost entirely through changes to the ‘pliable’ rules regarding alienability that do not require public engagement.

In this section, I begin by addressing the broadening of intimate altruism in Ontario to include non-biologically related individuals, and the subsequent challenge of distinguishing between prior emotional relationships and newfound friends among potential donors. Next, I discuss the extension of *community altruism* to non-directed living donors—anonymous donation to a common person within a community, often conceived of as a uniquely charitable act. I then provide an analysis of paired and list-paired exchanges, which enable donors to trade a kidney in exchange for either the queue jumping of their intended (non-compatible) recipient to the top of the deceased donor waiting list or acquiring another donor’s kidney. Finally, I turn to recent changes surrounding the reimbursing of donors for expenses incurred in the donation process, which I interpret as a narrowing of the gift. Recalling the distinctions made in chapter 3 between rules of altruism and alienability, only this last change introducing donor reimbursement implicates a rule of altruism by pushing the boundary-rule regarding the prohibition against “valuable consideration” offered in exchange for a kidney.

8.2.1 Change 1: *The Boundaries of Love—Broadening Intimate Altruism*

In 1985 in Ontario, the major debate among transplanters was about whether to permit living kidney donation from unrelated individuals within families, namely spouses. Beginning in the 1990s, biomedical and social forces as well as patients and transplant providers pushed the boundaries of who can donate by expanding donor eligibility criteria, thereby extending categories of live kidney donors. The boundaries of *intimate altruism* therefore began to shift as definitions of who was considered an intimate expanded. Table 18 identifies the various years in which each newly accepted category of living donor emerged in Ontario.

Table 18 *Donor Subtype Acceptance by Year for Living Kidney Donors in Ontario*

Year	Donor Subtype
1954	Identical twins only
1980s	Biologically related only
1992	Non-biologically related family members (spouses, then in-laws)
2000	Biologically unrelated (aka LURD) but emotionally-related
2007	Non-directed
2008	Paired exchange

As we saw in chapter 4, it was during the 1990s that transplant centres in Ontario began to slowly relax the rule prohibiting kidney donation from non-blood related kin. When asked about unrelated donors, several donor team interviewees immediately provided a biomedical explanation. After the cyclosporine breakthrough in 1982, experiments at transplant centres worldwide which were reported in the academic literature determined that higher doses and new forms of postoperative immunosuppressive pharmaceuticals were successful in avoiding the

rejection of less compatible, unrelated donor kidneys. Justification for using unrelated donors was at minimum derived from positive medical outcomes.

Spouses were the first *unrelated*—meaning non-biologically related—family members allowed to donate. At the large transplant centre included in this study, a donor team member with over twenty years of experience said that opening the door to such unrelated donors and thereby expanding the definition of intimate altruism became medically acceptable and was demanded by “the consumers of healthcare” (DT4). In other words, potential recipients and potential donors “were really pushing the envelope of...who we would consider as donors” (DT4). She explained the shift in policy from the early 1990s and 2000s to the time of the interview, in 2010, as follows:

We used to have this really paternalistic line where we would say, “I’m sorry, you have to have an established emotional relationship with your recipient. And you’re just a member of the church congregation. Please go away.”

But you know years ago that’s what we would do because it really was so difficult for us to wrap our heads around. And we got challenged enough on it that we thought, “okay, we’re really going to have to revisit this and think this through.” Because who are we to define what a relationship is?

You know that we don’t have the old traditional nuclear families anymore. It’s “everybody who considers themselves kin with somebody else,” and it’s very different than you and I may define it, but it’s not to say that it’s wrong. And then by 2000 we were saying, “come on board, you broke bread together, sure we’ll look at you” (DT4).

Describing their previous policy as embarrassing, a donor team social worker explained that the transplant centre found itself on weak ground in the face of accusations of Eurocentric paternalism:

For example in the Filipino culture. The term *cousin*, everybody is a cousin. And they really mean it. But they may have never met. They may have talked through their aunts; talked through their uncles. But for some reason they feel that there is some connection. Whether it be spiritual, emotional. And they were challenging us because they were saying, “it’s not the length of the relationship. It’s the quality of the relationship” (DT5).

Interviewees raised separately, but not in connection with this issue of ‘who is family,’ the challenge of uncovering relationships of subordination. The literature on living donors recognizes that there are issues of gender and hierarchy and it is the job of the donor team social worker in particular to ensure the donor-recipient relationship is healthy. It is well recognized that more women donate than men, although more men acquire End-Stage Renal Disease. In this discussion, above, we see another pressure added to the work of the social worker which is the implicit accusation of racialization should the transplant centre reject an extended family member.⁹²

By 2010, a potential intimate donor was considered acceptable as long as they had a *prior emotional relationship*, sometimes described as an *emotionally longstanding relationship* with the intended recipient, signalling the shift toward a more open-door policy for potential donors.⁹³ With this shift, however, came an increased reliance on psychosocial scrutiny by donor team members. In other words, instead of ruling out potential donors based on whether or not they are related to the recipient, donor teams now proceed on a case-by-case basis assessing, as discussed above, the legitimacy and acceptability of each potential donor-recipient relationship on its own merits. Getting to know the potential donor has thus become increasingly important.

Transplanters explain that one important divide among the pool of transplant candidates with living donors is the country of origin of the donor. In Canada, intimate donors are not only preferably close relations but also preferably Canadian citizens or citizens of a resource-rich

⁹² Notably, I found the social worker included in this study to be very time-pressed due to insufficient funding creating a high volume workload of multiple duties within the renal unit, donor evaluation being only one of them.

⁹³ To put Ontario in context, the trend toward open eligibility has not been moving at the same pace and necessarily in the same direction in every jurisdiction. An interviewee noted that some jurisdictions, like the United Kingdom, “were really slow to come on board” with spousal donors and that “there are many hospitals who weren’t willing to even consider donor recipient pairs unless they were genetically related, up until, I dunno a couple years ago. Ten years ago [2000]” (DT5). By 2000 in the United States, the JAMA guidelines did not prohibit unrelated donors, signalling the acceptance of such donors. However, the international Amsterdam guidelines of 2004 note that kidney donation from unrelated persons is illegal in Mexico and in some European countries.

country for whom entry visa requirements are waived. Unlike transplant candidates with relatives in resource-rich countries, candidates from resource-poor countries often face many challenges in bringing their kin—and thus potential intimate donors—to Canada, a difference that generally creates a racial divide among the pool of transplant candidates. Potential donors who require a visa to enter Canada must assure immigration authorities that donation is likely (with evidence of blood type compatibility), that medical costs are covered, that the sale of organs is not taking place, and that they will return home after the donation (Hindustantimes, 2013).⁹⁴ Another issue facing non-resident intimate donors is transplant centre responsibility for postoperative donor health, especially in the long term. As with all individuals who do not qualify for Ontario Health Insurance Plan (OHIP) benefits, the standard disclosure to potential donors regarding implications for complementary health insurance (and other types of insurance) coverage – that they may no longer be covered or their premiums may increase – is even more salient for non-residents.

Two instances of blurred lines between prior emotional relationships and newfound friends in non-kin potential donors were reported at the large transplant centre included in the study. Staff at the centre characterized these cases as involving “aggressive” potential recipients. In one case, a potential recipient’s husband, who was disqualified from donating, brought a Buddhist monk from Burma to Ontario for potential donor evaluation. Sometime after the donation took place, the Burmese monk contacted the transplant centre and sought their support in applying for refugee status in Canada. After this incident, donor team staff began explicitly advising potential donors that they cannot expect anything in return for their kidney donation. At the time, rumours were

⁹⁴ Transplanters have lobbied the federal government to facilitate the travel of potential donor family members from resource-poor countries requiring entry visas. One partial success has been the special “organ donor visa” created in 2006 by Citizenship and Immigration Canada.

circulating that some Canadians were targeting religious adherents, specifically Buddhist monks, in their search for altruistic kidney donors.

In another case, known as the “Australian cult” case, an out-of-country donor had intended to donate to an Ontarian he had met on *matchingdonors.com*. The large urban transplant centre included in this study created a new separate protocol, for “Internet Solicited Living Kidney Donation” for handling such cases, which was then used as the rationale for rejecting this particular donor. It stipulates that such donors are defined by having “little or no pre-existing relationship to the recipient” (St. Michael's Hospital, 2010). They will be evaluated by the same standards “with the added requirement of an evaluation by the donor team psychiatrist” (St. Michael's Hospital, 2010). Based on a literature review, the protocol identifies that the following issues can arise in these donor-recipient relationships,

undue pressure to donate in responding to an emotional appeal to donate, emotional and financial exploitation; potential psychological risk of donation may be increased compared to any benefits when the outcome of the transplant candidate is unknown (St. Michael's Hospital, 2010: 1)

After the initial rejection at this centre, the dyad nearly had the kidney exchange performed at a second Ontario transplant centre. However, at the last minute, the centre rejected the donor when his parent called to oppose the nephrectomy based on the claim that their son was a member of a cult. As with a few other rejection cases in Canada, this case became publicized after the incensed potential recipient told their story to media. Ontario newspapers reported that the potential donor’s religious group, the Jesus Christians, encourage members to donate a kidney. The pair eventually had the procedure performed at a renal transplant centre in Cyprus (The Edmonton Journal, 2008).

For this transplant centre, the question of who counts as an intimate provoked concern that intimate altruism could slip into a commerce mode of exchange. The question for donor team evaluators was thus one of motive—why would such a person donate their kidney to a complete stranger, especially if they had to travel all the way to Canada to do it? The suspicion of monetary exchange notably reveals that for transplant centre staff, kidneys are not given as *pure* gifts. Thus despite the public exaltation of living donors as selfless heroes, intimate altruism necessarily entails *exchange*—a kidney for the psychological benefit of seeing a loved one flourish. Without both a pre-established loving relationship informing *normal* acts of care and the continuation of a relationship that would allow the donor to witness the benefit of donation to a recipient, two questions arise. Why would someone donate their kidney? And why donate to *this particular* recipient? Importantly, the creation of a new category of donor, complete with specific protocols, does not mean the automatic rejection of such potential donors. Not directly included in this study is the large urban transplant centre that *did* approve the first and only publicly disclosed case in which a donor was publicly solicited over the internet.⁹⁵ Special categories and protocols can thus be used as much to permit donation as to be grounds for rejection.⁹⁶

Perhaps inevitably, the shifting and stretching of boundaries for intimate altruism donation practices and eligibility has also led to the creation of a new boundary—the donor category of *internet public solicitation*—as a means for transplant centres to provide a clear rationale for rejection. As such, the line of acceptability for potential kidney donors has moved but has not

⁹⁵ Jenny Oad was permitted to give her kidney to Mike Fogelman in 2003. The pair met on *livingdonorsonline.org* after Jenny responded to Mike's (paid) advertisement, in which he announced that he was searching for a kidney donor (Oad, 2004).

⁹⁶ Indeed, warranting further study is the role that protocols and guidelines play in the management of controversy. In this study, documents were also found to have greater or lesser use and relevance based not only on content and applicability but also in relation to the divide that arises between policy/protocol creation and practice.

disappeared. At the large urban transplant centre included in this study, collapsing all potential donors who knew (even minimally) their intended recipient into one single category led staff to create a new category called “publicly solicited by internet donors.”

Right at the boundary lines of intimate altruism—but still contained within it—are cases where potential donors respond to public solicitation but while also already being acquainted with the intended recipient in some way. Such potential donors are counted as *emotionally related* or *sufficiently related* for donor evaluation purposes. At least three such cases have been reported in the media in Ontario. While donor team members insisted that details of the nature and length of such relationships carry weight in the decision, by virtue of merely “breaking bread together” such donors are officially categorized as legitimate. By contrast, potential donors who come into contact with their intended recipient through the internet solely for the purpose of kidney exchange are deemed illegitimate and are viewed with suspicion.⁹⁷

8.2.2 Change 2: Community Altruism for Living Donation—Non-Directed Donors

The broadening of social eligibility criteria for living donors has also been observed in the development of what can be considered *living donor community altruism* in the form of non-directed or stranger donors. As in deceased donation, non-directed donors give anonymously—at least initially—to an end-stage renal disease patient who is at the top of the deceased donor waiting list. However, as Boas (2011) puts it, in giving to a stranger within a community, this type of exchange is generalized much like the way in which Richard Titmuss (1970) promoted altruistic

⁹⁷ Contributing to this change and other changes to donor categories is the emergence of new intermediaries for facilitation of kidney exchange between donors and recipients. While Ontario transplant centres remain the ultimate intermediary, a host of internet sites and individual activists now also broker altruistic (and commercial) organ exchange.

exchange through public blood donation (as addressed in chapter 2). Around 2000, a number of renal transplant centres in the United States began accepting living anonymous donors, or *Good Samaritan* donors as they were first called. In the 2000 JAMA guidelines, the non-directed donor is defined as an individual who seeks to donate to a transplant candidate who is unknown to them. This study found that the way in which Ontario renal transplant centres came to view this form of altruism as ethical, legitimate, and justified illustrates how the status of new ideas can shift over time from controversial to acceptable. The standard story for non-directed donors is that these unique and seemingly selfless individuals pushed the system, repeatedly approaching different centres over time and insisting that they were not psychologically unstable. The doubt by intermediaries was captured in a brief news article:

Many hospitals won't accept altruistic kidney donors, and there are few resources to help donors navigate their options. The hospitals' reluctance grows from concerns that potential donors may be psychologically unstable, likely to change their minds and, perhaps, receiving payment for their kidneys...Advocates point to the UNOS transplant list - where nearly 75,000 people are waiting for a kidney - and argue that *the nation needs kidneys*. Amid pressure, a few hospitals are starting to loosen policies (Press, 2007, emphasis added).

In general, use of non-directed donors is understood to signal a broadening of acceptance of risk of harm to strangers by the transplant community (Adams et al., 2002).⁹⁸

The first non-directed living donation in Ontario, called “anonymous donation” at the time, occurred in 2007. By 2010, fifteen people had donated a kidney as non-directed donors. Non-

⁹⁸ The significance of extending community altruism to organ exchange between living persons has been interpreted differently elsewhere. Boas (2011) finds what I call community altruism challenged by data from the United States showing a rise in the intimate altruism (what he terms “restricted altruism”) of direct donation. He interprets this as a trend toward privatization that may be a steppingstone to a commerce mode of exchange. My view identifies the emergence of community altruism in living donation as a countertrend that works to restore the balance between community giving and inter-personal giving, at least in principle if not in volume.

directed organ donation was deemed ethically acceptable as long as the same criteria for donor evaluation of directed or intimate donors—those who have an intended recipient—were also met. However, with non-directed donors, “careful attention to the psychosocial evaluation” and that suitability be assessed on a case-by-case basis were additionally recommended (JAMA, 2000: 2924). Transplant centre staff, in accordance with guidelines, reported greater thoroughness in assessing such donors, rendering them “resource intensive” donors. In terms of organ allocation, the JAMA guidelines advise the same rules as for deceased donation, which are based on principles of objectivity and fairness, ensuring anonymity, as well as need. This thus clearly situates non-directed organ exchange within community altruism.

There is debate, however, regarding the idea of allowing non-directed donors to select a specific subgroup of intended recipients. Allowing directed donation by anonymous living donors “remained controversial” among JAMA (2000: 2924) conference participants. The objection is that donation conditional upon a recipients’ sex, race, class or other grounds, “...could present an ethical obstacle for the transplant team...[who] is otherwise obligated to distribute organs by an objective plan that fosters equity, irrespective of a social class or group” (JAMA, 2000: 2924). Some participants in a study comparing Quebec and French renal transplant physician views notably argued that if directed, “the act is no longer truly altruistic. In their view, altruism implies donating to anybody, not a member of one’s community” (Fortin, Dion-Labrie, Hebert, Achille, & Doucet, 2008). Others expressed ambivalence, “they knew that if they refused the conditions, they would lose a kidney,” and identified some conditions acceptable, for instance if the donor wants a child to receive their kidney (Fortin et al., 2008: 150).

The account of a non-directed donor interviewed for this study is consistent with accounts by transplant centres. In the midst of continuous public campaigns promoting consent to deceased

donation, it dawned on Luanne, “Why wait? I’m healthy. I can give a kidney now.” She attributed her eureka moment to a *Globe and Mail* article that featured Jenny Oad, a public solicitation direct donor. The article discussed how Jenny was part of a ground breaking set of sequential donors, each one inspiring the next. This group included: (1) Sheryl Wymenga, another Canadian public solicitation direct donor who donated at a renal transplant centre in the United States because such exchanges were not yet allowed in Canada (Oad, 2004); (2) Zel Kravinsky, a wealthy American who gave all of his money away, and then his kidney too, through non-directed donation to a woman he later met; and (3) a non-directed donor who is also a priest, Father Pat, who preaches live organ donation online. Luanne thus added herself to this club of individuals who could be characterized as *righteous rebels*.

In my interview with her, she stated that her decision to donate was deliberate, and she also took it up as a moral cause. Luanne proudly achieved the goal of being the first non-directed donor at her local renal transplant centre. She was close to tears when she told me about her nearly being rejected on medical grounds. Like those before her, Luanne had to push transplant centre bureaucrats for permission to donate. Accompanying Luanne throughout the experience was the online community of people on public message boards at *livingdonorsonline.org*, which is also where Jenny—Luanne’s inspiration—chose her intended recipient. Luanne said that during the three-year process of her donation, she visited this website and participated in online discussions on a daily basis.

Transplant centre staff said that they received annual offers of non-directed, anonymous donation but only started taking such calls seriously after American centres began allowing non-directed donations. A key study by transplant experts in British Columbia titled “Living Anonymous Donors: Lunatic or Saint?” (Henderson et al., 2003) contributed to the shift in thinking

that such individuals may not be psychologically unstable or godly but rather “unique, charitable people” (DT1). This research pointedly revealed the extent to which those who mediate transplantation—namely, transplant centre staff—understand organ donation as an *exchange* as opposed to a unilateral *transfer*. The article raised one concern that parallels a common objection to commercial exchange—that anonymous, non-directed donors would not bear witness to a recipient flourishing as a result of their sacrifice. Ultimately, however, this was overcome by the idea that knowledge that one performed a morally praiseworthy act was an equivalent—or at least sufficient—psychological return on investment.

The broadening of criteria in the form of living donor community altruism serves two useful functions for transplant centres. On the one hand, the possibility of donating to the community in such a generalized fashion has provided transplant centres with a means of responding to the perceived threat of publicly solicited donors, in particular the risk posed for principles of equity in transplantation. In other words, because success in finding an organ donor through public solicitation is seen to depend on social capital, degree of patient activism, and the recipient’s popularity (i.e. how compelling one’s story is) – as opposed to the urgency of medical need – centres seek to counter the perceived moral hazard by themselves determining who should receive an organ. In a donor team member’s words, “sometimes it’s just better to let us decide” (DT2). And for this reason, as of 2006, it became official policy for transplant centres in Ontario to inform solicited donors of the option of non-directed donation (L. Wright & Campbell, 2006). From a prospective recipient’s perspective, this is a clear form of gatekeeping as it undermines and potentially derails the time, effort, and psychological investment devoted to finding a potential donor.

On the other hand, living donor community altruism also aids transplant centres, given the standard practice that centres do not engage in soliciting live donors. Recent practices in Ontario show that transplant centres use examples of non-direct donation as justification for breaking the norm against publicizing living donation. At the time of writing, the live donor liver transplant program at Toronto General Hospital posted an online video featuring a dozen first hand positive stories of partial liver exchanges including both non-directed donors and donor-recipient pairs (University Health Network, 2012). Canadian Blood Services (2014) likewise posted an online video featuring the story of a non-directed donor as a means to raise awareness for living donation. In this video, a non-directed female donor tells her story through a single-person narration. She tells us how she decided to donate her kidney to the person most in need at her local transplant centre. Not only did her nephrectomy go well, but she is also pleased with her contribution to the greater good. Such videos can be interpreted as forms of solicitation which parallel the public exhortation of deceased donation community altruism. In this way, the extension of community altruism to living donation works to legitimize public solicitation. Alongside donor recognition ceremonies,⁹⁹ media stories, and other similar public exposure developments, living donation is *de facto* no longer exclusively an internal family matter.

Although non-directed donation became more accepted over the period studied, it is not accepted everywhere and does not sit easily with all transplanter medical providers. Notably, non-directed donors remain especially controversial in higher-risk non-renal transplants such as liver

⁹⁹ Over time, as the pool of donors shifted from related and intimate donors to more unrelated donors, it became not only acceptable but appropriate—important even—for transplant centres to semi-publicly recognize living donors. As such, toward the end of the 2000s, transplant centres began hosting biannual living donor ceremonies. This practice parallels the emergence of annual ceremonies hosted by the Trillium Gift of Life Network which memorialize deceased donors and distribute medals to deceased donor kin.

transplants. The emergence of non-directed donors have led to at least three ethical issues. The first was noted by a donor team member who expressed concern that the long-term psychological outcomes for these donors remain unknown (DT4). The sense is that without bearing witness to the benefit received from their kidney, non-directed donors may not fare as well in the long-run. Second, some anonymous donors seek to meet their recipients after the donation and transplant. Ontario transplant centre policies vary in response to such requests, reflecting an ambivalence about such encounters. The altruistic rule of privacy, identified in chapter 3, was designed in ‘Gift Acts’ with deceased donation in mind. To uphold this rule, transplant centres allow and facilitate letter exchanges between donor and recipient at a minimum (in the same fashion as organ procurement organizations perform this task in deceased donation). At one centre in Ontario, a hands-off approach is taken, with the centre refusing any facilitation of such encounters, while at another centre, a meeting is arranged no sooner than six months after the organ exchange if both parties are in agreement (DT4)(University Health Network, 2008). Third, as we saw above, some non-directed donors seek to partially direct their donation by adding conditions on who receives their kidney (see Fortin et al., 2008).

8.2.3 Change 3: Paired and List-Paired Exchanges

While patients were pushing the boundaries of who was considered an intimate, and the rare individual was stepping forward to donate a kidney in life rather than death, transplant medical providers were innovating two new forms of kidney trading—*paired exchange* and *list-paired exchange*. Paired exchange is the exchange of kidneys between immunologically incompatible dyads who are entered into a registry and matched using an algorithm. As we see below, this kind

of trade or swap system became organized nationally in 2009 in Canada.¹⁰⁰ List-paired exchange allows an immunologically incompatible living donor to provide a kidney to the patient at the top of the local deceased donor waiting list in exchange for their intended recipient receiving the next available deceased donor kidney, thus moving them to the top of the waiting list. Both paired and list-paired exchanges emerged in the 2000s at renal transplant centres and on regional or national scales in a few countries including Canada.

In paired and list-paired exchanges, altruism is *bent* by pushing up against lines of distinction that separate intimate and community altruism, and, that separate altruism and monetary modes of exchange. First, we will recall from chapter four that community altruism is defined by a large population of residents or citizens where strangers give organs to strangers within that pool, and intimate altruism is a direct form of exchange defined by a personal relationship between donor and recipient. Paired and list-paired exchanges create a category in-between intimate and community altruism. Membership in this community, defined by names listed on a database which constitutes a pool of potential kidney exchanges, requires transplant candidates have potential donors. Notably, likelihood of receiving (in other words status within the pool) drops for hard-to-match transplant candidates (due to blood-type or antigen sensitivity) and rises for each potential donors a single transplant candidate brings into the pool. One view is to see the inequality among transplant candidates in intimate altruism – where candidates are divided by access to potential donors – solidified by the exclusion of the latter group, candidates without potential donors. Exacerbating this divide, list-paired exchanges, whereby the donor gives to the person at the top

¹⁰⁰ As we saw in chapter 4, incompatibility arises from blood type or donor-specific antibodies in the potential recipient.

of the list in exchange for their potential recipient jumping to the top of the waiting-list, removes one person off the list but bumps down all of the remaining waitlisted transplant candidates, who are on the list because they do not have a donor. While the effect of list-paired exchanges was seen by interviewees as not ideal, the view taken by all parties is that raising the possibility of a match and a transplant is always a good development. A transplant for anyone trumps equity in allocation issues. And, notably, being within the community of paired or list-paired exchange is no guarantee of an exchange. Allocation of kidneys thus proceeds somewhat unfairly, like in the case of intimate altruism, even if potential recipient chances improve. Instead of exclusively depending on their own concentric circle of intimates for a kidney, registered potential donors expand their potential donor pool to include the size and proportion of blood types within the registry.

Second, what sets these *trades* further apart from the convention model is the tangible return. At first glance, and justifying this system, list/paired exchange donors give their kidney for the same psychological return on investment of seeing their intended recipient flourish. But, although donors do not receive money in exchange for their kidney, they do receive something tangible—a kidney. To meet their end goal, list/paired exchange donors receive the immediate return of either queue jumping their intended recipient to the top of the deceased donor waiting list or acquiring another’s kidney. The donation here is a qualified one, based on an expected return rather than being given unconditionally or solely for the intangible return of psychological benefit. Nevertheless, the love justification of intimate altruism donation remains intact in this type of exchange and is conceptualized as working across or in tandem with another donor-recipient pair.

In 2000, JAMA guidelines conference participants reviewed the ethics of paired and list-paired exchanges and declared that “such exchanges were not considered to be a form of commerce as suggested by some who are opposed to this approach” (JAMA, 2000: 2923). Pilot projects were

conditionally endorsed with two caveats. First, it is only seen as fair that the recipient know what they are getting: “potential recipients should be given full disclosure of the donors’ medical characteristics as they pertain to quality of the donor organs” (JAMA, 2000: 2923) . Second, it was noted that beneficial and adverse consequences of the exchange system should be monitored, in particular for any impact on the blood type categories of transplant candidates on the deceased donor waiting list. Further, the JAMA guidelines recommended that paired exchange nephrectomies be performed simultaneously in order to avoid the hazard of one donor declining after the other donor procedure was completed. Support for list-paired exchange was justified on the grounds that it increases the total number of organs available, while also not adding to the list of patients waiting for deceased donor organs.

At the 2004 Amsterdam forum, one question raised was whether kidney exchanges constituted organ exchange “for valuable consideration” as prohibited under section 301 of the US *National Organ Transplant Act* of 1984. Here it was noted that paired kidney exchanges are illegal in some countries, such as in Australia, on the grounds that such trades are not considered to be altruistic. However, this was countered by another, unelaborated view according to which “receiving a transplanted kidney is not the same as getting a monetary value; and that although it is obviously of value, it is not the same as buying and selling organs” (TTS, 2005: S62).

In 2000, Premier Harris’ Report recommended an investigation of paired exchange, stating that it “gives rise to ethical issues.” There is no evidence that the province undertook this work. By 2007 the next major public policy report, the Ontario Citizens’ Panel report, expressed enthusiastic endorsement for paired exchange. In keeping with the optimistic tone of the report, which endorsed all types of donation—especially living donation—as solutions to the organ shortage crisis, the authors envisioned an all-inclusive live donor pool. Panellists stated that the

pool of potential donors would not be limited to incompatible dyads. Any of the twelve million Ontarians wishing to donate could be registered in the pool so, “every recipient could find a match” (Ontario, 2007: 17).

In the mid-2000s, the two larger live donor renal transplant centres in Ontario began offering list-paired exchange. This change came about with no media attention. It is not clear that patients on the deceased donor wait list were made aware that they could receive or lose their position in the queue as another candidate is moved to the top of the wait list when such exchanges take place. Around the same time, some centres started facilitating simple ‘swaps’ involving four individuals whom comprised two sets of incompatible donor-recipient dyads. In Ontario and Canada, the media heralded paired kidney exchanges as successes and there were no public objections. Intermediary publicity in Canada—e.g. by Trillium Gift of Life Network and Canadian Blood Services publicity—is also overwhelmingly positive. As in the Citizens Panel, the broader public views kidney trades and chains as logical solutions to the problem of organ incompatibility.

When Canadian Blood Services conducted a review of current developments in living organ donation in 2009, the practice of paired and list-paired exchanges was described as follows:

In a paired donor exchange, two recipients essentially “swap” willing donors. While medically eligible to donate, each donor is an incompatible match for his or her intended recipient. By agreeing to exchange recipients—giving a kidney to an unknown, but compatible individual—the donors can provide two patients with healthy kidneys *where previously no transplant would have been possible* (Canadian Blood Services, 2009: 5).

The emphasis in the above passage is on enabling a transplant candidate to receive an organ. The review went on to describe safeguards “to ensure fair exchanges,” including anonymity “to avoid undue pressure on the donors,” simultaneous nephrectomies, and transplant surgeries. The only challenges identified in the review were of a logistical nature.

The same year, 2009, Canadian Blood Services launched a national Living Donor Paired Exchange program. As explained above, an algorithm is run four times a year to find linked matches within the incompatible dyads donor pool. A potential recipient may bring in more than one potential donor to increase their odds of being matched, but the number of kidney trades that will be included in one sequence (known as chains) are limited to involving four pairs. By 2010, some data on the national Living Donor Paired Exchange start being recorded but list-paired exchange data remain invisible. Overall, the number of exchanges having occurred for either type of paired exchange is not made explicit in public reporting.

Notably, in 2010 non-directed donors start being leveraged in the Living Donor Paired Exchange program, which works to justify and further legitimize both non-directed donation and paired exchange. The length of chains is extended by inserting a paired exchange sequence of kidney swaps between a non-directed donor and their unknown recipient—the transplant candidate at the top of the deceased donor waiting list. By *triggering* a chain, the post-operative status of non-directed donors is further exalted as having saved even more lives. And the benefit of helping not only the most needy in the community but of also saving the lives of more end-stage renal disease patients is noted as a way to encourage publicly solicited donors to switch from directed to non-directed donation.

Overall, this study found that renal transplant centres were sensitive to the ways in which inequalities in allocation of deceased donor organs develop among transplant candidates based on biology. In 2012, Canadian Blood Services stated its intention to launch a registry of highly sensitized patients for those with higher numbers of antibodies against human tissue as a result of events such as pregnancy, blood transfusions, and prior transplants. However, according to one donor team member whom I interviewed, “there are some issues with [paired and list-paired

exchanges], in terms of equity,” as they tend to “stack” certain blood types, consequently prolonging the wait time for some candidates (DT4). The other equity issue, of course, is the qualified entry into the trading pool that potential recipients must have a potential donor to participate. When Kelly, one potential recipient I interviewed, uncovered that both of her potential donors were not blood compatible with her, she felt it was too much to ask of either of them to consider paired or list-paired exchanges. One donor team member similarly had observed that many potential donors want to donate directly, and *not* to a stranger. As mentioned in chapter 4, for some incompatible pairs, desensitization techniques that render the potential recipient’s body more receptive to a kidney from a potential donor are emerging as an alternative.

8.2.4 Change 4: Narrowing the Gift—Compensating Donors

The fourth change observed in the rules and practices surrounding donation is the reimbursing of donors for expenses incurred in the donation process. In 2008, after three years of living donation inactivity, Ontario’s organ procurement organization, the Trillium Gift of Life Network, launched a Program for Reimbursing Expenses of Living Organ Donors. In doing so, TGLN adopted a mediating role in living donation that did not infringe on the territory of transplant centres. This change, which I interpret as a narrowing of the gift, poses a more direct challenge to the status of kidney donation as an altruistic exchange than the three changes reviewed above. It confronts the ‘rigid’ rule of altruism prohibiting exchanging anything of “valuable consideration” for an organ.

As we saw in chapter 2, Parry (2008: 1134) critiqued calling tissue exchanges involving money “compensatory fees” instead of “a price charged to secure the resource or commodity.” In her view this is false. From the interpretive lens of Viviana Zelizer (also presented in chapter 2), there is no falsity because money is modified by culture. By using the words compensation or

reimbursement, the culture of altruism marks the money given as supportive and indirect as opposed to a price or payment which would imply remuneration. My interpretation is that this framing of the use of money conceptually narrows what constitutes the gift to the ‘thing’ itself (the kidney) rather than the larger process of the act of donation. This kind of boundary pushing is creative. Kidneys acquire a partial commodification status – what Philippe Steiner called quasi-gifts – that this is seen as legitimate and therefore does not breach the gift-market boundary. The pool of potential living donors is enlarged through this change not by making an offer to people who need money but, half-way, by including people who cannot otherwise afford the cost of the process of donation.

It is also possible to interpret the public acceptance of living donor reimbursement as a form of redress for negative aspects of donation that society can alleviate. Little can be done to reduce the physical suffering, especially the pain all of my living donor interviewees spoke about experiencing in the immediate post-operative period, and, the long-term suffering of one interviewee (Julie) to the point of needing a transplant herself.¹⁰¹ Through this logic, the costs of parking, travel expenses and the risk of losing a job, become the visible and permissible suffering of the donor that society ought to minimize while the ‘cost’ of adverse outcomes that some donors pay remain outside public view.

Since 1985, numerous public policy reports identified “financial burdens” on living donors as a problem that ought to be rectified by compensation. In 2000, Premier Harris’ Report stated

¹⁰¹ Note that another interviewee, Carl, was also a kidney donor who later needed a transplant. This change in status from living kidney donor to potential recipient for a kidney differed from Julie’s change in status (from living kidney donor to potential recipient for double-lungs) most significantly on two counts. First, he dissociated his later renal problems from his nephrectomy. He told me his kidney failure was cause by an inherited condition and he was not displeased that this was not detected during his living donor evaluation tests. Second, he was not suffering. He had received a kidney transplant from his cousin, and, was in good health at the time of the interview.

that such economic hardship was unfair and a barrier. At the international level, as seen in Chapter 7, the 2000 JAMA guidelines similarly declared that living organ donors “should not personally bear any costs” and that lost wages should be defrayed (JAMA, 2000: 2925). Given that the next topic, within the same section, is a review of the debate over “direct financial compensation,” there is a link subtly made between the two topics, reimbursement and remuneration. The 2004 Amsterdam guidelines make no mention of money. And, by comparison, the 2006 CCDT guidelines dissociate the link by excluding all discussion of the debate over paying donors. Recognizing the “economic hardships” of donors as a barrier to donation is the sole issue raised in regards to the use of money in relation to donors.

Between the 2006 CCDT forum and the 2007 Ontario Citizens Panel report, “financial risks” came to be defined as a key “barrier” inhibiting more living donors in Ontario and Canada. As the CCDT definitively stated, “there is a need to reduce the financial risk to the donor and address concerns reported by living donors” (CCDT, 2006: 2). The Citizens Panel, for its part, sought to interpolate empathy for living donors: “None regretted donating and all would do it again in the same circumstance. However, each and every one experienced hardships they had not anticipated when they were making the decision to donate” (Ontario, 2007: 14-15). Further, an important statistic was identified: “about 24%” of live donors are “lost” due to anticipated financial hardships” (Ontario, 2007: 15). By casting living donor expenses in this light, a wrong was implied, and the solution—to give donors money—was thus positioned as a moral corrective.

Thus, while purposefully avoiding any appearance of commodifying the organ, living donors still act altruistically while some of their costs are minimized. In this way, Ontario’s reimbursement program represents a policy change that bends altruism – a select interpretation of

the “no money” clause in Ontario’s *Gift Acts* stretches this donor protective rule without breaching it.

8.3 Invisible Donors within Altruism

As we saw in chapter 2, scholars of commercial organ exchange raise alarm that the fate of organ sellers is invisible. Without denying that problem, research conducted for this study found that the phenomenon of invisibility is more generalized. As initially addressed in chapter 4, the long term health of living donors within altruism is also invisible. The acquisitive and recipient-centric focus of organ supply strategies has taken priority over numerous calls to establish a living donor health outcomes database (G V. Ramesh Prasad & Garg, 2006; Ross, Siegler, & Thistlethwaite, 2007). This is especially a concern given the expansion of donor medical eligibility criteria occurring in transplant centres in other jurisdictions and the rise in the numbers of living donors overall.

In this final section, I review what is known about medically complex donors and discuss adverse outcomes for living donors. Transplant centre autonomy is raised as key to this development. From the perspective of donors and potential donors taken in the thesis, the implications of the lack of public visibility of donors whose health may be put at risk and/or whose stories are not positive are weighty. Not only are all outcomes important for informing living donor eligibility criteria in transplant centres, exposure of these cases diminish the legitimacy of the initial forays by government agencies in promoting living donation (addressed above in section 8.2.3) as well as the general dominance in the media of only good news stories.

8.3.1 Medically Complex Donors

There is literature based on American transplant centre experience that documents and debates the progressive expansion of medical eligibility criteria for living donors. As identified in chapter 3, this sub-group of donors are called, “medically complex donors” (and sometimes “marginal” or “higher-risk” donors) because they have, for example, well-controlled hypertension, mild obesity, or stable psychiatric disorders. The analogous category in deceased donation is called, “expanded criteria donors” and is comprised of donors with medically compromised organs. These categories reflect the shifting of ‘pliable’ rules undertaken explicitly to enable more potential donors to donate.

Whether Ontario transplant centres have expanded medical eligibility criteria for potential donors was not investigated or revealed in the research conducted for this study. A background document prepared for the CCDT Living Donors Forum did find through a limited survey that transplant centres vary in their acceptance of medical criteria (Cockfield, 2006) which was confirmed in my interviews at transplant centres.

The relevance of broadening medical eligibility criteria is raising the risk of harm for potential donors. People who step forward to be evaluated embark on the process alone. They have no organization or institution – other than on-line forums such as we saw earlier (e.g. *livingdonorsonline.org*) – to provide information independent of their transplant centre or to share information with other potential donors. Ontario transplant centres, self-defined as “ethical,” are lacking a system of accountability. This might catch, for example, the fact that donor education material does not raise the issue of medical uncertainty, including the depth of the knowledge base, degree of interpretation of test result and changes in acceptable test result thresholds. Moreover, there is no recognition of this category of donors and their health outcomes in the public realm.

In the United States, the rise in living donors is at least partially attributed by many observers to the broadening of not only social but also medical eligibility criteria. For example, Rodrigue and colleagues (2013:770) note the following:

In the United States, the expansion of living-donor eligibility criteria is well documented. This includes not only expanding the types of donors who are acceptable candidates (e.g., unrelated, anonymous non-directed, older donors) but also the medical and psychosocial eligibility criteria. Many more programs have shifted practices and are now willing to consider donors with well-controlled hypertension, mild obesity, and stable psychiatric disorders.

This quote clearly conveys the extent to which transplant centre autonomy is central to broadening the ‘pliable’ rules of donor eligibility criteria.

In a 2008 medical textbook on living donation, this sub-group of donors is defined by conditions “that connote an increased risk to either the donor or recipient in terms of renal function, kidney allograft survival, or patient survival” (Gruessner, Taranto, & Gruessner, 2008: 15). Notably, reviews of research published in these kinds of textbooks not only seek to evaluate but also to improve the acceptability of medically complex donors by prescribing lifestyle changes (Gruessner & Benedetti, 2008). Improvements to health that potential donors could or should undertake prior to being accepted as a living donor include smoking cessation, rehabilitation for narcotic additions, and weight loss for obesity.

One issue raised by the use of medically marginal donors is ensuring informed consent. The Amsterdam guidelines recommend the use of an epidemiological method that estimates the risk of developing end-stage renal disease, and which distinguishes between medically complex and normal donors, as the way to ethically resolve issues around medically complex donors. According to the guidelines, “the ethical position of transplant centres could be best validated if kidney donor candidates were presented a defensible and quantitative estimate of medical risk [...] of 1 in 10, 1

in 100, or 1 in 1,000” (TTS, 2005: s62).

Other observers insist that informed consent must be informed by better research which, in turn, requires systematic data collection. Davis (2010: 1873) argues that,

Almost one quarter of living donors have medical conditions that may be associated with future health risk. Close follow-up and a registry of these donors are necessary. Only then will we be able to inform prospective living donors most accurately of the real risk of donation on their health and survival.

The call for a donor health outcomes registry is thereby heightened by the recognition of medically complex donors. Monitoring immediate and long-term health is needed to ensure donor protection.

An issue connected to the use of medically complex donors is the prospect that the health status of the population is changing. The identification of more ill health among the overall population, as Rodrigue and colleagues (2013) found, could signal better detection, or, that the health of the population is changing, thus leading to more incidences of end-stage renal disease and consequently reducing the size of the pool for potential live kidney donors.¹⁰² What is important is that the mortality and morbidity risks that are quoted to potential kidney donors are based on research of the same sub-group, and not on a more (or less) healthy population. This link notably challenges the presumption we saw earlier by demographer David Baxter and the Ontario Citizens Panel report that the living donor pool is limitless.

8.3.2 Public Awareness and Responsibility for Adverse Outcomes in Living Donors

Overall, the public is not made aware of adverse outcomes for living donors. Live donor media coverage Ontario is recipient-centric, positive, and promotional. And, as we saw above, in starting to promote living donation, TGLN and Canadian Blood Services – both government agencies

¹⁰² As new diagnostic techniques become available, more refined evaluation is possible (Rodrigue et al., 2013).

mandated to increase the volume of organs, – is not taking a neutral stand. The message conveyed is that live kidney donation works well for both parties. When risks are mentioned they become part of the technical details addressed later, once potential donors start down the pathway towards donation. Living donor stories tend to be reported soon after the exchange. Missing are follow-up stories of donors' health status twenty years later and the spectrum of possibilities that occur. There is an absence of tales of relationships that flounder instead of deepening. And, especially absent are stories of donors with adverse outcomes.

Two live donors interviewed for this study, with opposite long-term outcomes, illustrate the imbalance in what becomes publicly known about living donation, and suggests that the post-operative health of the donor influences which story is more frequently shared. When I interviewed her, Maureen (mentioned in chapter 5) had initial complications from her 'plank' (open) nephrectomy (not laproscopic surgery) and was treated poorly by the hospital but was in good health twelve years after donating at age 48 to her appreciative 30 year-old brother whose health improved thanks to her kidney. She told me,

I did have a bit of health problems, at first, I ended up with a hernia. I must say, that's when the system failed donors...I think it's changed since then, but, when I went back to try and get help...I went back to the co-ordinator, sort of, 'where do I go to get help. [their reply was] 'go back to your family doctor.' 'Yeah, but she doesn't know what you did.' Because the pain was pretty bad (it was a year before I could wear anything around my waist, and I actually had further surgery to correct it), because they finally found out what had happened. And I'm fine now, but, I mean, once you gave the kidney, 'okay, you're gone now. And, I found that really disconcerting. That wasn't helpful. It kind of gave me a bad taste. But, I know that things have changed because I was part of a study. I don't think I was the only one in that position. And, I know they've changed some policies since then, so, I don't know exactly what they are but there is more donor support.

Once these medical problems were all taken care of, Maureen resumed her normal life. She retained her job and became an organ donor advocate, speaking publicly at promotional events for TGLN. She promotes living donation.

My health is fine now. I had no bad effects from the loss of the kidney, it was just, I scar really badly, apparently that's what caused all the problems. So I was fine, and it was about a year after my full recovery, so two years after the transplant that I started getting involved with TGLN. I've done a lot of speaking to various different groups, to try to educate people on organ donation and to get them over that 'ick' factor. I speak to a lot of new Canadians, especially, and it's really interesting, how people react. I really enjoy doing it and I do a lot of it.

By contrast, Julie, who donated her kidney to her 64 year-old uncle seven years prior at age 55, had lost her job and was isolated at home, tethered to an oxygen machine and hoping to qualify for a lung transplant. She feared ineligibility because she only had one kidney. Not only was her short and long-term health outcome poor, the psychological benefit of seeing her uncle flourish did not come to fruition. He died a year later from cancer caused by the immunosuppression drugs. A passing comment made beforehand has stuck with Julie. She told me that as she arrived on the day of the donation, "he introduced me not as his loving niece but as his kidney." And after he died, family rumour was that his wife complained about the quality of the kidney she gave him, saying, "'well it didn't last long'." Julie speculated that her aunt was jealous of her close relationship with her uncle which was heightened by the donation. As a result, Julie never saw her uncle again.

In her own words,

I think I'm an unusual case. Um, anything that could go wrong, went wrong. And as a result, I'm suffering. I don't think it's usual. However, uh, from my experience I would say that I don't think that live donorship is that great an idea. If I had my way they would make it mandatory when anybody died that they would donate their organs.

But live donorship I think, um, is a double-edged sword. I was in great health. I was speed walking two miles a day every lunch hour. When my uncle was dying and I offered to donate my kidney, we were a match. Which was wonderful.

So uh the whole year of 2003 I went through testing and most of 2004. And in December 2004 I donated my right kidney and woke-up on oxygen. I was then informed that I had emphysema. And I'm thinking, 'well I didn't have a problem before the surgery and after a year and a half of testing and blood tests and x-rays and CT scans and...[sighs] heart tests and psychological testing. I was perfect, as a donor. And how come all of a sudden I have emphysema and asthma?'

And um...it was a hard thing for me to deal with because I was so healthy. I had a lot of pain in my back. Um, they herniated a disc in my back when I was on the table. Because I never had back problems before the surgery. Uh, they said I would be in the hospital for four days. I was there eleven. I was on full oxygen the entire time. Actually I almost signed myself out. They suggested I might be able to go home one day and I just, I just walked out.

As Julie put it, hers was "not a good story." Like Maureen, Julie also had the 'plank' procedure and mentioned that she also had a blood clot in her lungs and her remaining kidney failed to work initially. She was disappointed in her medical care before the operation, describing it as "cold;" afterwards, she lost complete trust in her medical care. As noted in chapter 1, when probing whether and the extent to which her medical problems were caused by the nephrectomy, her family physician said, "we failed you. The medical profession failed you" in approving her as a living donor.

Julie also spoke of her donation as selfish as she especially regrets not thinking beforehand about the impact of what she now sees as her self-inflicted poor health on her husband.

I donated my kidney because I believe it was the right thing to do at the time. But maybe I had a little bit of hero in me with my uncle, you know. And I was kind of let down. I think I was let down by him and his wife more than anything.

But uh...I just didn't luck out...And everything I read about kidney transplants. You can live well with one kidney...That's something I did not consider and I'm kicking myself for it: I never considered how my dutifulness would affect my family. All I could think was, I zeroed in on my uncle. I never thought well if something happens my husband is going to suffer too. I just never, you know?...I did it because it was the

right thing to do at the time. If I knew now then what I know now, no I wouldn't have done it. And that's a fact.

This is the story that is not heard in public. The invisibility of stories such as Julie's lead to the kind of 'structured forgetting' we saw in deceased donation. The consequence is that taking collective responsibility for living donor health outcomes is not on the "ethical" or policy agenda. In exactly the way the donor team nephrologist I interviewed feared, Julie regretted the donation but absorbed the blame instead of registering a complaint. She was forgiving, telling me, "but I've never taken it any further. What am I going to say? People make mistakes. People are human." In response to the commonplace view that kidney donation is a minimal risk, she said, "I think that donation is fine as long as A, that you're healthy, and, B, that you're young. I think over forty it's hard on you. I really do."

As we saw above, in section 8.1.8, some American living donors with adverse outcomes have started to raise their voices to shift responsibility from themselves in agreeing to the risks of donation to transplant centres and governing organizations. Notably, among a range of objections, one donor in this group expressed dismay at the inability to connect with others in her situation: "My abandonment worsened when I realized there were no non-profit or community-based organizations for living donors. Everything was recipient-oriented" (C. Wright, 2012: E10). When I asked an interviewee who held a senior position in an Ontario organization working to prevent renal disease whether living donors were included in their view of who needs renal care, she looked surprised. This had not occurred to her (Tx7). The critical perspective offered by this nascent collective of adverse outcome living donors is a call for less 'structured forgetting' of their experiences and more donor protection. They argue for rules to ensure transplant centres take responsibility for donor health outcomes and greater public awareness of the risks of living

donation. Moreover, these donors call for a shift in thinking – that they be considered for their own experiences apart from those of the recipient. In my reading, they want there to be a place within the transplant world for their viewpoint. In their words, “if we are to respect the gift, we also must respect the giver. People are more than medical supply.” (C. Wright, 2012: E11).

As a whole, my living donor interviewees had mixed experiences in their health status post-nephrectomy. Exposure to knowledge of health risks assumed by donors as well as hearing stories of adverse outcomes reveals that government sponsored intermediaries and the media are recipient-centric in their positive portrayals and promotion of living donation. Asking for kidneys is seen as appropriate because the risk is considered minimal. Hearing these stories returns us again to the call for a living donor health outcomes database which was publicly called for by transplant physicians in 2006 and recommended in several medical guidelines reviewed in chapter 7. The deeper concern is whether and to what extent persuading people to donate depends on the absence of negative information. Is it possible for *all* living donors within altruism to be included, instead of forgotten, in what is known about kidney exchange without detriment to the goal of increasing organs? Transparency about what is at stake – and *for whom* – is a requirement of democracy and of ethics.

8.4 Conclusion

This chapter focused on the on-the-ground realities of living donor kidney exchange in Ontario. Here I examined how, in negotiating between the recipient-centric/donor-protective tension, transplant centre staff interpret ethical action in at least two ways. First, they employ cautious procedures in their evaluations of potential donors in line with the guidelines reviewed in Chapter

7. However, the ability to be ethical is not always straightforward. It is also complex and challenging and not subject to external scrutiny.

Second, the Ontario and Canadian transplant community has broadened living donor eligibility criteria and endorsed novel ways of exchange as a means to expand the organ supply in Ontario. Here, altruism as a concept is extended, bent, and in one case narrowed, in order to increase the likelihood of kidney donation. However, while more living donors are made eligible, many remain invisible, particularly medically complex donors and living donors who experience adverse outcomes.

In the next—and final—chapter, I conclude the thesis by revisiting the central argument, recapping how deceased donation and living donation are practiced in Ontario and pointing to areas for future research.

Chapter 9 Conclusion

The study was set out to understand the social relations of kidney exchange through transplantation in Ontario by identifying and analyzing what enables and inhibits exchange, with an emphasis on select aspects of exchange: prioritizing donors, and the mediating role of mezzo-level actors. What was uncovered through the research process was that kidney exchange is more complex than is suggested by conventional wisdom. This led to my argument that the focus on altruism, through a discourse of donation, deflects attention from another set of significant political sites and processes – those of alienability that legitimize organ removal. This served as the basis of my explanation for the disjuncture of *structured forgetting* which I demonstrate exists in Ontario. Importantly, it was shown how the assignment of two of three rules of alienability were granted to the medical profession in *Gift Act* legislation. As a result, the public is not required to be engaged in changes to a variable shown to be fundamental: donor eligibility criteria that establishes boundaries around the pool of potential donors.

A sociological puzzle about how donors are understood in the public realm formed the focal point of the study. I found in Ontario of a lack of scrutiny for a clear policy failure, and an inconsistency between public discourse and expert action regarding the variables that matter to the goal of increasing the deceased organ donor rate. Living donors in Ontario were also publicly exalted whilst the boundaries lines around who is eligible are pushed and contested, and there is no accountability for adverse outcomes. The pattern in Ontario fit an observation made by critical scholars of a disjuncture between what is publicly seen and known about organ donors, and knowledge about how kidney exchange works that does not inform debate, either evidence ignored

or an imbalance in public information about each side of the exchange equation, of recipients and of donors. To describe this puzzle I embraced and extended Nancy Scheper-Hughes term, *structured forgetting* which captures the sense that the forgetting is at the societal-level, and is structurally embedded in the organization of exchange. I argued that the disjuncture between the public and experts arises in altruism, and proposed that there is therefore a relationship of power at stake that exists regardless of the mode of exchange.

The findings of the study represent only one possible interpretation of kidney exchange as it is organized within altruism (with a few exchanges occurring outside Ontario on capitalist and authoritarian bases). I argued that that there is a tension between donors, recipients and intermediaries that is imbalanced by a recipient-centric orientation. And, further, that the focus on increasing organ donation, set within an altruism versus market framework, deflects attention from a significant variable: the legitimacy and limits of removing kidneys from their owners – in other words, alienability.

Evidence to support the central claim of the study led to my theoretical account of transplantation, presented in chapter 3. The account constituted half of my argument, the other half being my claim that a *discourse of donation* deflects attention from competing explanations (which I found more persuasive, and which therefore inform my theoretical account of how kidney exchange through transplantation to works). Saving the analysis of the *discourse of donation* for chapter 5, I began my contribution by laying out an argument to demonstrate that kidney exchange is complex with respect to donors because of a tension that is created between the demand for kidneys and the constraints on its supply: kidneys must be relinquished without causing harm. The two variables I ascertained to be most determinative of kidney exchange are altruism, and

alienability. This shifts the dominant frame of reference from gifts versus markets to bring alienability into view.

To support this claim, I returned to the history of transplantation and the foundational legislation of *Gift Acts* that enabled organ and tissue exchange by setting limits. Herein I identified two fundamental dimensions of transplantation, one that reveals the source of tension between donors and recipients, and the other that shapes how kidney exchange is governed. First, is the recognition of a conflict of interest in the *declaration of death* rule which requires two physicians separate from the transplant team declare the donor dead, legitimizing organ removal. This donor-protective measure constitutes recognition that valuing kidneys ahead of persons is an inherent threat created by and through the therapeutic modality of transplantation. Second, I identified an important division in how rules are legitimized, four by legislation (consent, terms of exchange, privacy, and death declaration), which renders this set 'rigid' to change; and two by medical guidelines (death diagnosis and living donor beneficence and non-maleficence), which renders this set more 'pliable' to change.

After acknowledging three broad contextual dimensions necessary to transplantation, I argued that acquiring organs entailed a process of objectification comprised of three parts: 1) establishing a source of organs, in other words a pool of potential donors from the living and dying; 2) governing rules of altruism and alienability to establish and limit the pool; and 3) rules also govern techniques of converting potential donors into actual donors. I refer, below, to this alternative way of understanding organ exchange as the theoretical framework of *rules, pools and conversion*. I then focused on alienability to argue that what makes organ removal legitimate is the boundary-work of limit-setting reflected in medical guidelines that include and exclude persons from the pool of potential donors. By locating the authority over alienability to the domain of

medicine, the public did not have to be consulted or engaged whatsoever in a central variable of kidney exchange for transplantation: determining who should be considered a potential donor, and altering the boundaries around the population of potential donors. Relatedly, a central pillar of my critique is that decisions regarding the legitimacy of organ removal are not merely medical matters but are also social constructions that call for public deliberation. Returning then to my original research question, I found that what enables and constrains kidney exchange in Ontario are the rules governing altruistic exchange, the pools of potential donors, and, the techniques of conversion.

Notably, the *rules, pools and conversion* framework shifts the conventional understanding of kidney exchange by locating the significance of consent to donation and hospital efficacy to aspects of conversion that aim to shift potential donors to become actual donors. I argued that the central ideational technique of conversion is what I call recipient-centrism. Drawing inspiration from sociological theories of knowledge as directional, this concept was created to articulate an orientation in thinking that inserts the ‘other’ of the potential recipient in the life of, or medical treatment of, the potential donor. In many respects, recipient-centrism creates the potential donor in the abstract, but the ideational manifests materially as this orientation in thinking is structurally embedded into medical practices, for example, as we saw in chapter 6, by *clinical triggers* for donation. Recipient-centrism was argued to be inherent to kidney exchange through transplantation, and at the same time it is countered by donor protection. The rise of living donor protection detailed in chapter 7 demonstrated a more explicit contestation over where to draw lines along a continuum situating recipient-centrism at one end and donor protection at the other. Most importantly to my overall argument is the claim that recipient-centrism exists regardless of the mode of exchange. What this alternative way of understanding kidney exchange does is shift away

from the gift-commodity binary to accept markers other than money – such as donor health outcomes – as grounds for drawing boundary lines between the legitimate/ethical exchanges and illegitimate/unethical exchanges. This resituates the commonplace view of Ontario’s altruistic regime as unproblematic and ethical, in comparison to market exchanges, by raising awareness of shortcomings and forms of power unrelated to monetary exchange.

9.1 Answering the Sub-Questions

The study presents a comprehensive understanding of the social relations of kidney exchange in Ontario. The organization of both deceased donation and living donation are illuminated and processes of change are elucidated. Yet, the sub-questions asked at the outset of the research process remain difficult to answer. I asked, when is asking for or offering a kidney appropriate? My response is that the legitimacy of alienability, and aspects of altruism, including degree of recipient-centrism, determine the appropriateness of asking for and giving kidneys. Deep desires to give that reflect recipient-centrism can be denied by the inalienability of organs as determined by physicians following medical guidelines. Asking for a kidney by government sponsored intermediaries (TGLN, Canadian Blood Services, and transplant centres) is also seen as more appropriate on the basis of community altruism as opposed to intimate altruism. We saw in chapter 8 that Canadian Blood Services is starting to promote non-directed living donation on this basis. Overall, the more alienability is taken-for-granted, the more appropriate it is (and even obliged it is) to request and to offer a kidney in deceased and living donation.

Another sub-question was to ask about how aggressive we should be, as a society, and are we aggressive enough in seeking kidneys to heal ourselves, our spouses, our children, and our

friends? This question was not answered by the research. Original evidence generated in the research process does nevertheless inform such determinations by explicating another way to look at the evidence than relying on conventional accounts, especially the *donors per million* measure. The need for kidneys to heal ESRD patients is indisputable, and the good news is that the waiting list is slightly declining. Determining that the deceased donor system is performing at a level of approximately 50 percent effectiveness means that improvement is possible. Showing the shortfall between the waiting list and size of the pool of potential donors reveals that efforts beyond 50 percent more effectiveness are futile; the only way to heal this set of patients is to reduce their numbers by preventing renal disease or using other therapeutic modalities. With respect to living donation, a consideration not part of standard accounts is the need to ensure the health of the general population to ensure people qualify to be living donors. The constraints on organ supply also point to the improvement of dialysis as a necessary and worthwhile strategy.

Another sub-question was: what is the effect of how kidney exchange is organized? This question has multiple answers. TGLN was demonstrated to have raised the annual rate of deceased donation, including the consent rate. There is no evidence available on why, exactly, people consent or refuse consent to deceased or living kidney donation. However, a loose presumption of causality would point to the ‘discourse of donation’ as effective in contributing to consent to donation. However, the ‘discourse of donation’ was also found to have a negative effect by creating blame, and racialized blame, for the organ shortage. In living donation, the same presumption of causality for rising rates of living donation holds while the downside is clearly the lack of accountability for adverse outcomes.

Further, I sought to know the extent to which responsibility is taken, especially collectively, for any harms incurred as a result of kidney exchange. The answer to this question is again mixed.

Efforts to deter transplant tourism represent a donor protective reaction that acknowledges, and attempts to mitigate the potential culpability of nephrologists at transplant centres for illegal exchanges of Ontarians buying kidneys outside Canada. Aside from this isolated effort, the recipient-centric orientation of all aspects of the organization of kidney exchange limit collective responsibility for transplant outcomes, especially for donors. Responsibility for donor outcomes is especially hindered by the paucity of data collection tracking who is deemed eligible to donate, and post-operative health monitoring. Both the political dominance of organ shortage as the only issue of concern, and narrowness of organizational mandates are structural barriers to the kind of responsibility called for by the study.

Finally, through these questions, applied to this case, I sought a deeper understanding of altruism as a mode of exchange. What is revealed by the study regarding altruism specifically remains unclear. Initially, I developed a critique that the downside of altruism, especially in an explicit consent regime, is the need to promote information deemed persuasive in order to secure consent to kidney donation. And the persuasive push on information was demonstrated to strain frankness; information becomes a subject of contestation. I am less convinced at the end of the study, however, that this downside is attributable to altruism *per se*. Given my finding that the threat of valuing kidneys ahead of persons holds regardless of the mode of exchange, it follows that information about donor nephrectomy may be contentious regardless of the mode of exchange. What may be more critical are systems of accountability that establish trust in the intermediaries that facilitate kidney exchange. What can be said about altruism, based on the findings of the study, is that this mode of exchange is not an unquestionable, morally-praiseworthy system. The rule prohibiting “valuable consideration” does work as intended to deny exchanges that are considered

suspicious of cash exchange. At the same time, the juxtaposition with capitalism contributes to insulating altruism from scrutiny.

In bringing the thesis to a close, my sense is that the work has only just begun. Below I recap the evidence used to substantiate the central argument and theoretical framework of *rules, pools and conversion* based on my analysis of deceased donation (in chapters 5 and 6) and living donation (in chapters 7 and 8). I then identify the contribution of the study to scholarship, as well as the theoretical and policy implications. Finally, drawing the work to a close would be incomplete without recognizing what remains unknown, priorities for future research, and final reflections on what this case tells us about contemporary biopolitics. Limitations of the study are addressed in chapter 2 in the methodology section.

9.2 Reviewing the Evidence

The argument made in chapter 3, providing a theoretical account of transplantation is addressed above and in the next section. Chapter 4, titled Ontario's Recipients, Donors and Intermediaries, shifted the study from the abstract to the concrete by introducing the case study of Ontario, especially giving important background information, presenting an original, quantitative profile of 8,151 kidney donors (4,616 deceased and 3,507 living donors) who provided 12,761 kidneys to End-Stage Renal Disease patients over 44 years, from 1967 to 2010. Insight into the societal-level relational links between recipients and donors could be gleaned from the details that are not usually provided: how deceased donors die, and how the pool of living donors is increasing and diversifying. Evidence is presented to show the failure by TGLN to meet the goal of doubling the annual deceased donor rate and the recent period as compared to previous decades. The positive impact of broadening of deceased donor eligibility criteria by embracing DCD in 2006 is also

illustrated. Among living donors, 28 organ providers from outside Canada whose kidneys were purchased by Ontarians are included in Ontario's donor population. The chapter ends by detailing the structure of two organ procurement systems – deceased donor *community altruism* and living donor *intimate altruism*. The distinctions between two types of altruism – community and intimate – provide an additional framework for making observations about change over time in subsequent chapters.

Chapter 5, titled Altruism and the Discourse of Donation, addressed what is known in the public realm by drawing upon a range of data sources (public policy reports, interviews, organ donor campaign material and the media) to demonstrate the existence of a dominant way of thinking about kidney exchange as the moral cause of organ donation. I called the dominant knowledge the *discourse of donation* and showed how it came into being, its core messages, sources, shifts in emphasis over time, and how it influences public understanding and public policy. Through this analysis, I demonstrated that the *discourse of donation* holds public attention on the rules of altruism – especially consent and, to a lesser extent, hospital efficacy – at the expense of an awareness of the importance of and changes to other variables. I argue that the focus on consent remained virtually seamless over the period of study (2000-2014) even though there is clear evidence that experts looked to other strategies, namely the new sources of DCD donors and living donation, by 2005-2007.

The analysis of the 'discourse of donation' included evidence detailing how the public is called into adopting a recipient-centric orientation through central messages: there is a need for organs, transplantation is successful, and everyone can help by consenting to organ donation. The need for donors to die, and die a certain way is dealt with by caveat in TGLN campaigns and in public policy. This 'detail' regarding the pool of potential donors is not allowed to interrupt the

optimistic focus of legacies and dreams, of belonging to community, and helping others. Through an analysis of immoral organ acquisition, I demonstrated how the *discourse of donation* rests on the gift-market dichotomy, further elevating and insulating the altruistic system from criticism. Organ donation advocates were also identified to show how TGLN (through their mass media campaigns in particular) is central in promoting the *discourse of donation* but not alone. Independent campaigns and journalists also promote the moral cause of organ donation and commonly use the *donors per million* population measure as a tool of persuasion.

The impact of the discourse of donation on public policy was also demonstrated. From 1985 to the period of 2000-2014 there was a shift away from evidence in public policy reports. Reviewing policy reports by Premier Harris in 2000, the Citizens Panel in 2007, and the Wait Times report in 2009, revealed that public policy is heavily influenced by the *discourse of donation*. Finally, the last section of the chapter shows how the conventional conceptualization of the problem – which ignore the donor pool – and the logic of blame on the system leads not only to advocacy for more investment in the altruistic system but also arguments for abandoning altruism. The pro-regulated market position is thus less oppositional than a logical extension of recipient-centrism.

Chapter 6, titled *Controversies in Deceased Donation: Seeing Donors, Protecting Donors and the Limits of Alienability*, turned to the other half of my argument for deceased donation to show both a competing explanation for the deceased donor rate, and the presence of recipient-centric – donor-protective tension that is rendered invisible in the *discourse of donation*. TGLN's work within hospitals was argued to create a new production process whereby hospitals no longer only heal the ill, they are also tasked with making 'medicine' by converting potential donors into

actual donors. Techniques of conversion lead to ethical concerns, especially over the temporal limits to acting on donors *for* recipients before donors are declared dead.

A different account of reasons for Ontario's failure to double the deceased donor rate was then presented through an analysis of TGLN conversion rate data. It was found that Ontario is improving deceased donor numbers, and improving its performance but still functions at only half of its full potential, with consent and death declaration variables at lower levels. It was also found that the size of the potential donor pool in Ontario is too small to meet the demand for deceased donor kidneys. Where a disclaimer was identified in each of three public policy reports (in 2000, 2007 and 2009) acknowledging that the size of Ontario's potential deceased donor pool may differ from other jurisdictions, data is now available to assess this question. My analysis demonstrates that the reason for the deceased donor organ shortage is both the size of the pool of potential donors, and the system; not just the system.

Finally, chapter 6 demonstrates recipient-centric – donor-protective tension through two case studies: contestation over the legitimacy of DCD as death, and the politicization of measuring deceased donors as a population. Notably, intermediaries were found to be in solidarity in regards to defending death but at odds in regards to measuring the deceased donor rate using the *donors per million* population measure, or the conversion rate measure. Together, chapters 5 and 6 demonstrate that the disjuncture of *structured forgetting* is constituted by the way attention to altruism draws attention away from the issues of alienability. This is how the social relations of kidney exchange through deceased donor *community altruism* is organized.

Chapters 7 and 8 turned to living donation which receives less public attention in Ontario even though it is on the rise. Unlike deceased donation, the challenges of imbalanced tension between donors, intermediaries and recipients are more apparent. Across the two chapters I linked

professional practice norms and rules established at the national and supra-national levels to the key site of kidney exchange: transplant centres. Evidence was presented to show that living donation is characterized by a quest to ‘find the line’ between the interests of recipients and donors that allows for organ exchanges from this source to expand “ethically.” As we saw in deceased donation, the visible contestation is over the terms of exchange of altruism, while the less visible pliable rules of alienability are staked out and shift largely out of public view.

Chapter 7, titled *Cash for Kidneys and the Rise of Living Donor Protection*, analyzed donor protective initiatives at the supra-national and national level. During this period, transplant abuses lead to efforts to protect donors and maintain the legitimacy of transplantation. Two efforts were analyzed: an anti-transplant abuse campaign, and the release of several medical guidelines. The campaign promoted deceased donor *community altruism* as the ideal form of exchange but inhibiting illegal exchange is hampered by a host of societal-level factors as well as global capitalism. Canadian efforts to deter transplant tourists are notable. A critique was also made that deterrence efforts are stymied by recipient-centrism, especially system blame and the suppression of information deemed dissuasive to securing consent to organ donation within altruism. In the second half, through a review of three medical practice guidelines, I demonstrated how guidelines – establishing the pliable rules in *Gift Acts* – delimit in a way that enables living donation to proceed and expand.

Chapter 8, *Constituting Altruism – Living Donor Kidney Exchange On-the-Ground in Ontario*, examined how kidney exchanges work in practice at the level of the transplant centre, and at the provincial level as influenced by public policy. As in chapter 7, what is considered ‘ethical’ and ‘legitimate’ is negotiated by processes that carve a line between the recipient-centric – donor-protective tension. At transplant centres, upholding “ethical” living donor kidney exchanges relied

heavily on coming to know the potential donor. This was usually unproblematic with the exception of aggressive potential recipients and aggressive potential donors, as well as potential donors whose eligibility fell into a grey zone of medical uncertainty. Donor protection was also found to be upheld in cases where monetary exchange was suspected.

At the provincial level, I showed how the logic of recipient-centrism made living donation more flexible through pushing boundaries of altruism and alienability. Four changes to living donation in Ontario were identified: counting more living donors as ‘intimates’; embracing non-directed donation; enabling paired and list-paired kidney exchanges; and compensating donors for their expenses. By loosening potential living donor eligibility criteria, the pool of potential living donors is expanded to increase the volume of kidneys available. This chapter closed by identifying how the population of living donors with adverse outcomes become excluded from public view, and transplant centre accountability.

9.3 Contribution

The primary contribution of the study is to offer an alternative theoretical framework for understanding the social relations and forms of power that enable and inhibit kidney exchange through transplantation. The *rules, pools and conversion* theoretical approach shifts the vision from two options of money or not, to a continuum of action, behaviour, institutional orientation, etcetera that reflect degrees of recipient-centrism within an inherent recipient - donor tension. Alienability is brought into view as a significant variable, at the individual and societal level, that is equal to if not more significant than the ‘to give or not to give’ question of altruism. Giving is only possible if and when a kidney is available for exchange. Thus, alienability is a central variable

that needs to be included in considerations of kidney exchange through transplantation in scholarly analysis and in public debate. I suggest that this framework and the concept of recipient-centrism, while needing to be tested and further refined, holds promise for explaining aspects of other body part exchanges, including reproductive forms of exchange.

At the mezzo-level, the contribution of the study is to call for the recognition of limits – the limits of finitude – using Gerald McKenny’s (McKenny, 1997) words, which I argue are best captured in the paradoxes of transplantation George Annas’ delineated decades ago (quoted again):

Shortage problems are also based on the nature of the organ shortage itself, which is largely an arbitrary construct built upon two readily-manipulable variables: patient selection criteria and donor selection criteria...As the success of organ transplantation has increased, the number of hospitals doing transplants has expanded, and so has competition for patients. Older and older, and sicker and sicker patients are now considered ‘suitable’ candidates for kidney, heart and liver transplants. This accounts for another paradox: as the number of organs procured increases, so does the number of individuals on waiting lists. *As long as the total number of transplant programs is uncontrolled, and patient selection criteria are undisciplined, there will always be an ‘organ shortage’.* (Annas, 1988: 621, emphasis added)

Some direct participants I spoke to wait patiently for a deceased donor kidney, or donate as a living donor and move on with their lives. But, as we saw in chapter 5 (and among physicians in chapter 6), a range of actors – from the average citizen to transplant physician,s to the Ontario and Canadian government – are deeply invested in the *discourse of donation* and do not see beyond it. Where the effect becomes a problem is when it turns into anger and blame – sometimes directed at racialized populations – that organs are not provided. And when the denial of an organ is used to justify patient activism buying kidneys illegally or through an authoritarian mode of exchange outside Canada. Directing blame on government for the lack of enough organs for transplantation is a misunderstanding of what is possible that is reasonably acquired given the dominance of the *discourse of donation*; as demonstrated, even the government promotes system blame. The gross

dissociation between knowledge of deceased donors, and the need for organs carries real consequences.

Recovering a sense of the full complexities of relationality in kidney exchange advances understanding of the reasons there are not, and are unlikely to ever be enough kidneys within altruism. This does not mean that all efforts at conversion should cease (50% more organs is possible), only that – as identified in the 2007 Ontario Citizen’s Panel report – expectations of what is possible need to be realistic. Until there is evidence to show otherwise, I am not convinced that a consciousness about limits would dissuade members of the public from consent to organ donation. The ‘culture of donation’ would benefit from greater transparency and accountability, as well as more reliable evidence.

Within the scholarship on organ exchange, the theoretical framework of *rules, pools and conversion* offers an alternative to the gift versus the market dichotomy. My theoretical frame differs by making the pools of potential donors visible, and contextualizing conversion techniques. Pools and conversion techniques are entwined: conversion techniques constitute not only actual donors but also potential donors, but remain nevertheless limited by the antecedent conditions that shape the size of the pool of potentials. If too few people die the right way, or new techniques for predicting the impact of donor nephrectomies deem more potential living donors ineligible, consent to organ donation has zero impact.

The *rules, pools and conversion* theoretical framework allows for specific and comparative analysis of each of these variables as determinants of different modes of exchange. As Cohen, Scheper-Hughes, Budiani-Subari, Moniruzzaman and many others identify, it is poverty (and often debt, sometimes sex/gender) that creates a pool of commercial organ donors. In Ontario, it is the antecedent events that lead to Catastrophic Neurological Conditions and death that create the pool

of deceased donors. And, for living donation, Ontario's pool of potential living kidney donors is created through: kinship and friendship; through trades among a subset pool of incompatible dyads (paired exchange); through the internet in rarer cases facilitating donor-recipient connections, and through encouraging non-directed donation. It is also constituted by other pools of kidney providers outside of Canada, engaged in exchanges for cash, and usually breaking jurisdictional rules. Upholding deceased donor *community altruism* as an ideal, within the altruism versus market dichotomy, blinds observers to the limitations of the pool of potential donors relied upon in this system. Every system identifies a pool; to be ethical and to make wise public policy decisions, the conditions of its making need to be a subject of analysis, and the relationality of donors to recipients rendered visible.

Other bodies of scholarship that address the role of the welfare state within global capitalism are also invoked by the study. The findings challenge the widely held view that the welfare state has contracted on every front by showing a realm within which the role of the state expands, and new resources are being redistributed. How organ exchange fits in moving against the general tide, and, how organ exchange fits within a capitalist economy also lies beyond the scope of the study.

Lastly, and related economically, the study illuminates the route through which tertiary care receives investment as opposed to primary care. The two populations of End-Stage Renal Disease patients, and Catastrophic Neurological Condition patients come into a relationship of kidney exchange in a dramatic fashion involving high levels of public and private-sector investment. Recalling that the greatest number of diagnoses that lead to End-Stage Renal Disease are preventable diseases: diabetes (Adult onset, Type 2; not Type 1) and hypertension; and, the most common causes of Catastrophic Neurological Condition for deceased donors in Ontario were

Spontaneous Intracranial Hemorrhages caused often by diabetes and hypertension, followed by motor vehicle crashes, head trauma, and drowning. As a comment on contemporary biopolitics, the conditions of injury and illness that lead to becoming both a potential recipient and a potential donor are largely preventable.

9.4 Implications

This research suggests that the threat at the individual level finds a parallel at the societal level: that there is a risk that the population of organ donors becomes valued for their kidneys ahead of their persons. Definitive evidence to show that either are happening in Ontario was not uncovered in the study. However, sufficient evidence was provided to identify the societal-level threat as a risk, and to show how it could arise subtly with the effect of skewing social investment in ways contrary to the public good and health of the population.

9.4.1 Theoretical Implications

By challenging the conventional problematic of how to increase donor/organ volume, the thesis suggests a different set of intellectual and pragmatic problems than is possible within the altruism-market dichotomy. The germane questions are: to what extent is it possible to set rules to govern kidney exchanges for transplantation that strike a balance between being supple enough to secure donors, and stringent enough to contain the threat of valuing kidneys ahead of persons? Equally important are questions raised by the study regarding forms of authority. Is the standard process within medicine appropriate to making decisions demonstrated to be social? And, how can

collective responsibility be taken for the outcomes borne by donors and recipients, living in Ontario and outside Canada?

What the theoretical model of *rules, pools and conversion* along with recipient-centrism offers are more variables, and degrees along a continuum for discerning what is legitimate and what is not legitimate. Importantly, the rules of alienability and the institutional level of how exchange is organized come into view. This opens up questions of donor protection unrelated to the use of money. Last, the study found that an important part of what is at stake in the organization of kidney exchange in Ontario is the foreclosure of grounds to object to a perpetual pushing of boundaries that risk compromising donor health, among other concerns.

9.4.2 Policy Implications

The study puts the wisdom of public policy into question and calls for a number of changes. Overall, it suggests a broader approach to improving the health of the population, and specifically for patients classified as potential donors to be seen and treated as vulnerable patients whose health during nephrectomy and afterwards is independently monitored and supported over the long-term.

The competing explanation for the deceased donor rate presented in the study also invokes the question of what can and should be done to increase the number of organs. A few options include: continue to expand the boundaries of the pools by further broadening eligibility criteria for deceased or living donors; change the rules of consent (towards more appropriation by the state or cash exchanges); or shift deceased donor maintenance temporal boundaries (to intervene earlier *for* donors)? The question of which variables have the greatest impact remains outstanding. And, contestations over these boundary lines, between recipient-centrism and donor protection will

determine the direction taken. Perhaps most importantly, how will we know when we have achieved success? If meeting the waitlist is elusive, then the pushing of boundaries is perpetual.

On the other hand, if it follows that none of the proposed changes, above, are acceptable for reasons of donor protection or for other reasons, and all that can be changed in deceased donor organ acquisition is in fact at the margins of the problem, these solutions may be fine as long as they are understood as such. What needs to change then, in my view of the evidence, are expectations and misdirected blame that is placed on “the system,” especially consent which, as I pointed out, is racialized.

Last, there is a distinct absence of an independent voice representing donors and independent voice representing recipients. Whilst potential and actual recipients champion organ donation, a quiet recognition of inequitable allocation of kidneys during the period under study suggests that recipients may benefit from organizing apart from intermediaries (see TGLN, 2013).

9.5 Areas for Future Research

Given the broad and thin design of the study, there were several issues raised within chapters 3 through to 8 where a need for more research was identified. Here I will reiterate several areas of research. But it must be said, first and foremost, that this study tells only half the story. What trumps the importance of deepening understanding of kidney supply is what this study excluded: the demand for kidneys, and, secondarily, the distribution and allocation of kidneys. There is an urgent need for a critical and comprehensive examination of how demand is created using a sociological approach that traces causality upstream. This is a priority because as stated, above, the possibility is raised in this study that public policy addressing the needs of Ontarians

suffering from organ failure – invested overwhelmingly in generating an organ supply – has become path-dependent. The Transplantation Society and especially its recent leader, Dr. Francis Delmonico advocates strongly for national self-sufficiency in organs. Ironically for this organization, and recognizing that more research is needed, the study suggests that an important contribution to national self-sufficiency may come from less, not more transplantation. Given the findings regarding the limits to the pool of potential deceased donors, national self-sufficiency may only be possible by reducing demand.

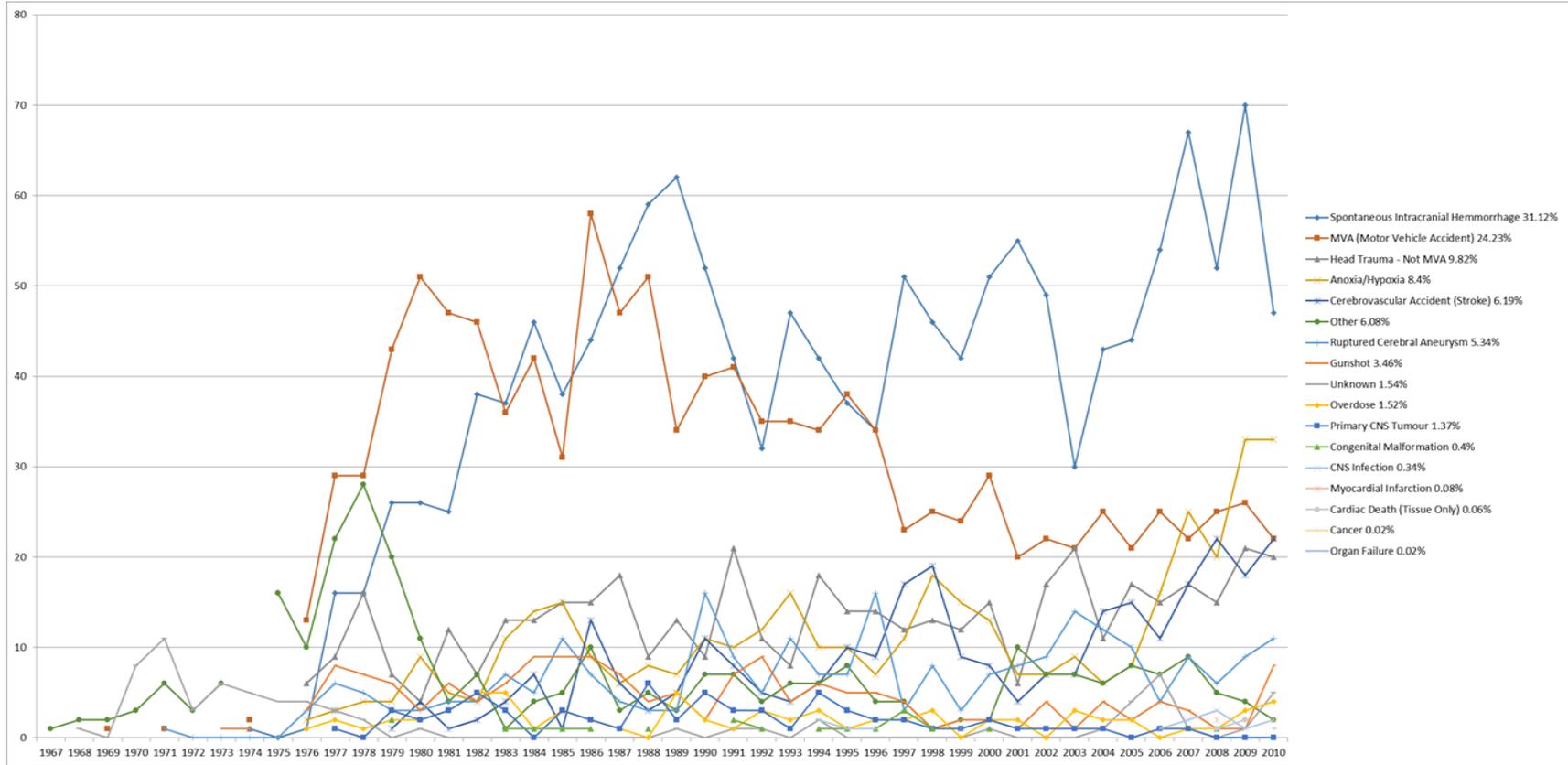
With respect to the supply of kidneys, four priorities are identified. First, thinking primarily of deceased donation, the extent to which consent to organ donation is sensitive to information deserves investigation. Is it necessary to “paint an excessively dismal picture” of underperformance in order to secure consent to donation or justify government investment (Vallis, 2001)? Second, a more fulsome explanation than was possible here is called for regarding the political salience of organ donation during this period. What role, symbolic and otherwise, does investment in organ transplantation play in relation to the welfare state? Also, how TGLN and allies use citizenship discourse, and the racialization of blame are important areas for future research. Third, I argued that the role of hospitals shifts through organ donation by making these institutions sites of production, not just of healing. We do not know enough about the on-the-ground changes in hospitals adjusting to the intervention of organ procurement organizations. Similarly, renal transplant centres are key sites where more research is needed on the social relations of exchange. The extent to which forms of social domination between donors and recipients are detected or not, the dynamics within transplant centres, and the grounds for denying or approving exchanges require research. Fourth, I also noted in chapter 5 that the role of the family vis-à-vis donor protection and benefit from organ donation is a theme that calls for further research.

It would be fruitful to examine the place of individuals in relation to their families comparing deceased and living donation and in light of the rights-based narratives that start to emerge in the *discourse of donation* around 2005.

9.6 Conclusion

Overall, the significance of this study is to recast scholarly – and ideally public – understanding of the social relations of kidney exchange. We cannot hope to take collective action for Ontarians buying kidneys abroad without also taking collective responsibility for the outcomes of kidney exchange in Ontario. As the exchange of various body parts continues to increase, so does the need to broaden our conceptual frameworks.

Appendix 1 Deceased Kidney Donors by Cause of Death, Ontario, 1967-2010



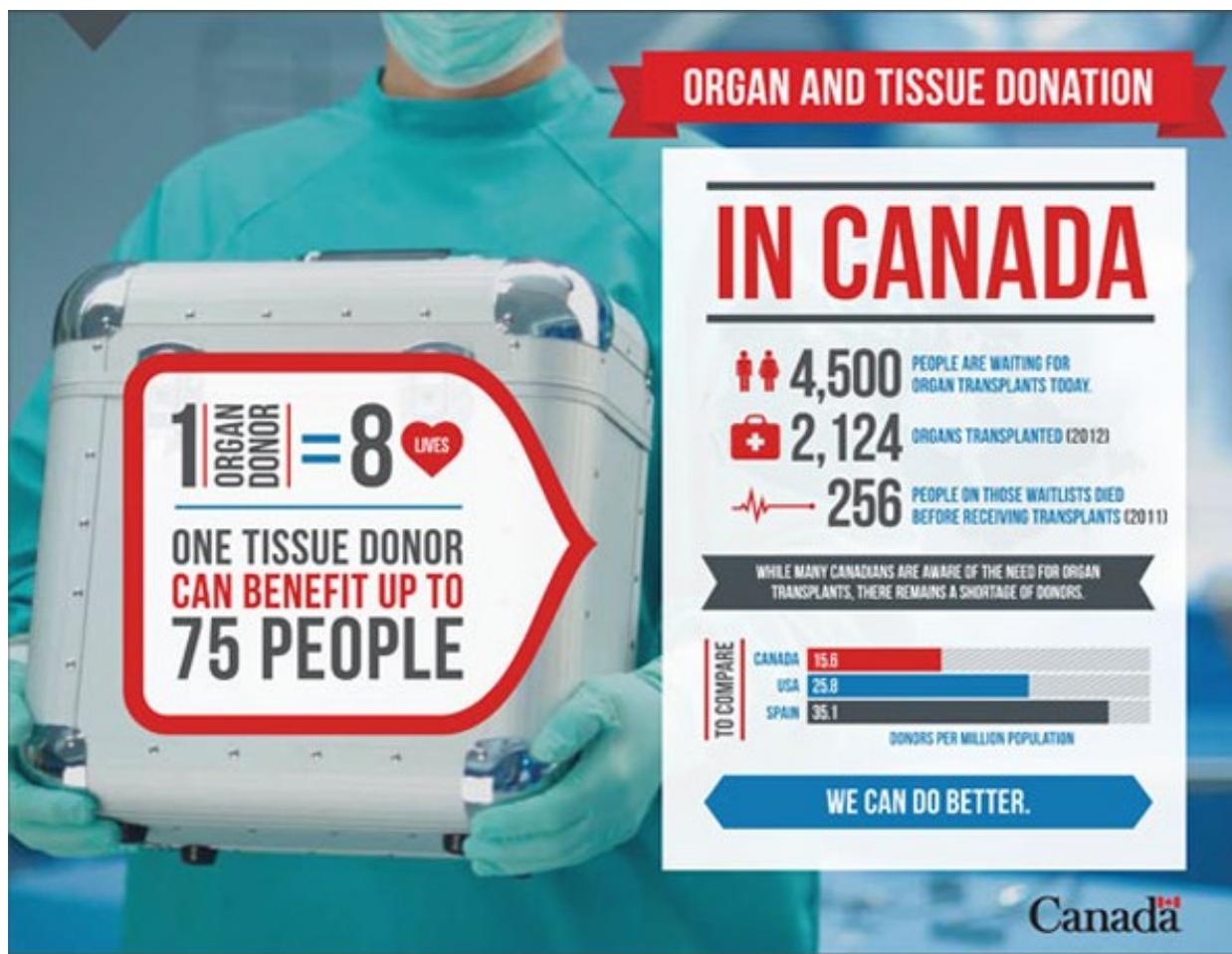
Source: TGLN TOTAL Database. Data extracted on May 13, 2011.

Notes: N= 4,616 deceased donors over 44 years from 18 primary diagnoses listed in the legend from highest to lowest; 1967 is the earliest deceased kidney donor on record.

Appendix 2 Health Canada Press Release Poster, September 27, 2014

“Minister Ambrose renews support for organ and tissue donation and transplantation: Helping to save and improve more lives through a nationally coordinated donor system”

“OTTAWA, ONTARIO - The Honourable Rona Ambrose, Minister of Health, today launched a new social media campaign to help raise awareness and promote organ and tissue donation in Canada. To mark the launch of the campaign, Minister Ambrose met with Mrs. Laureen Harper, MP Harold Albrecht and H  l  ne Campbell at 24 Sussex drive to kick-off the social media campaign, using the hashtag #GiftOfLife...”



Text, bottom half of right panel: “While many Canadians are aware of the need for organ transplants, there remains a shortage of donors. To Compare: Canada: 15.6; USA: 25.8; Spain: 35.1 Donors Per Million Population. We can do better.”

Source: (Health Canada, 2014)

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