

MAKING THE CHOICE, ORGAN TRANSFER OR TRADE: AN ANALYSIS OF  
CANADIAN VALUES AND THE POLITICAL ECONOMY OF CARE

A Thesis

Presented to

The Faculty of Graduate Studies

of

The University of Guelph

by

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In partial fulfilment of requirements

for the degree of

Master of Arts

July, 2011

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## ABSTRACT

### **MAKING THE CHOICE, ORGAN TRANSFER OR TRADE: AN ANALYSIS OF CANADIAN VALUES AND THE POLITICAL ECONOMY OF CARE**

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**This thesis investigates the role of Canadians in the international trade in human organs and the factors influencing patient decision making, assuming that patients make decisions regarding the management of their illness in a complex social, cultural, political and economic nexus. It engages a broad theoretical question of whether Canadians uphold values consistent with a commitment to consumerism, commodifying organs as needed and afforded, or altruism, supportive of voluntary organ donation systems. Semi-structured interviews were conducted with hemodialysis patients and their care givers in a southern Ontario hospital. Based on this analysis, Canadians appear to fall somewhere in the middle of the consumer-altruist divide. The dominant sentiment among participants was that Canadians ought not to be commodified, but the organs of foreign others in places removed from the Canadian value system hold potential, and provide opportunities for participating in a market when the supply of organs falls short of demand.**

## ACKNOWLEDGEMENTS

I would, first and foremost, like to thank my advisor, Vivian Shalla, for her tireless efforts and for the guidance she provided me throughout the process of completing my thesis. Her belief in my abilities and confidence in my work meant a great deal to me and helped me through both challenging and rewarding times.

Next, I would like to thank my committee member, Sally Humphries, who from the very beginning of my time at Guelph was supportive of my ideas and goals. Despite facing challenges of her own, she remained a committed and remarkable mentor throughout.

I would also like to extend my thanks to my examiner, Jeji Varghese, for her careful consideration of my work and thoughtful comments. Also, thank you, Jeji, for being a wonderful professor, mentor, role model and friend.

Additionally, I would like to thank the various faculty and staff in the Department of Sociology and Anthropology who contributed to my professional and personal development in a number of important ways: Elizabeth Finnis, Ken Menzies, Hans Bakker, Patrick Parnaby and Shelagh Daly, to name a few. I would also like to thank my professors in the international development program for opening my mind to a world of new challenges and possibilities.

I would like to extend my heartfelt thanks my participants who showed me such warmth and shared so much of themselves. Without you, this study would not have been possible. In addition, I would like to thank all of those individuals involved along the way and who helped plan and carry out this study.

Last but not least, I would like to thank my family and friends for their love, encouragement, ideas, guidance and support. I would not be the person, or the academic, I am today without all of you.

Thank you.

Amanda

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## **CHAPTER 1: Introduction**

Canada has an organ shortage. Today, approximately 4000 people wait for life saving organs that they receive through provincial organ donation programs. The longest reported wait time for a kidney in Canada was 11 years in 2006 (Zaltzman, 2006) and many people never receive the organ they need. This is a reality being observed in most post-industrial societies of the early 21<sup>st</sup> century (Scheper-Hughes, 2006). Aging populations, rising rates of diabetes that is a leading cause of kidney failure (Ministry of Health and Long-Term Care, 1999), a low number of “brain death” diagnoses that make a person fit for organ removal (Sharp, 2006), reduced risk taking, safer cars, and fear of the spread of HIV and other diseases (Baer, 1997), compound to create the supply problem. Furthermore, there is a general lack of communication between family members regarding individual donation wishes, as well as similarly ineffective communication within the medical setting, which suggests organs may be being wasted (MacDonald, Liben, Carnevale & Cohen, 2008). Those demanding organs are desperate and current transplant policies and donation as a supply strategy seem unable to keep up with the ever present and growing need.

Social scientists have developed theories to explain the discrepancy between organ supply and demand. Some have argued that the demand for medical services, such as organ transplant, is high due to advances in biotechnology (Illich, 1976; Rabinow, 1996; Scheper-Hughes, 2002/2003; Sharp, 2000). Indeed, with the release of the immunosuppression drug cyclosporine in the early 1980’s, and progressively better techniques for transplantation, more people turn to organ transplantation as the ultimate cure for a number of illnesses (Fox & Swazey, 1992). Others argue that it is the very

discourse of ‘scarcity’ of organs that drives the demand for organs worldwide (Scheper-Hughes, 2003). But, when considering the perspective of an ill person waiting for an organ that may never come, such assertions are arguably irrelevant. A person waiting for an organ understands that they have a need that must be fulfilled and the body and organs of the other become objects of desire; ‘life’ and the organs that sustain it become the “ultimate commodity fetish” (Scheper-Hughes, 2003). When the need cannot be fulfilled, desperation adds a new dimension to demand.

The international trade in human organs has been receiving a great deal of attention from international media and researchers, particularly within the last decade. They have uncovered the most heinous acts associated with organ stealing, trafficking, and the exploitation of the global underclass as organ suppliers. The trade marks a global degradation of notions of humanness and an ever more intense commodification of life under liberal capitalist ideologies. It is supported by bioethicists who bolster “right to buy and sell” mentalities to meet the needs of consumers and the goals of biotechnology industries (Scheper-Hughes, 2003). Wealthy buyers prey on individual indebtedness and inability to escape poverty that make the world’s poorest populations particularly vulnerable to participating in the trade (Scheper-Hughes, 2006). The attention and recognition of the trade over the last decade has also led to some significant government and policy considerations.

The debate questions whether governments should address organ shortages through legal-economic means. Some believe that the regulation of organ exchange through monetary compensation, whether by individual buyers or governments, is out of the question because of exploitation (Scheper-Hughes, 2006). In line with this, it has been

suggested that governments consider donation rather than commodification as it is seen as “more in harmony with the social policy of the modern welfare state” (Schweda & Schicktanz, 2009). Additionally, “anonymous gifting and charity towards strangers resonates with explicitly Christian values” (Scheper-Hughes, 2003), which is especially true for post-European-colonial North American nations. On the other hand, the main arguments for “commercialization” are: 1) “justice,” people should not die waiting for treatment, 2) “liberty,” the right to do what one wants with one’s body, 3) “beneficence and utility,” the win-win nature of both sides getting what they want, and 4) “efficiency,” an economic system will “solve the demand problem” (Schweda & Schicktanz, 2009). As of yet, many nations remain unsure of how best to proceed.

Recently, Canadian governments have been campaigning for live donation and increasing the number of registered donors (cadaveric donation) (Gift of Life, 2009). These strategies are the publicly and politically accepted ways by which to increase the supply of organs locally. Unfortunately, because shortages persist, some people turn to seeking out organs outside of legal-medical means. Within the current system, people have to wait and the international market is one alternative they might consider; there is evidence that Canadians are participating in the trade. Doctor Jeffrey Zaltzman (2006) of St. Michael’s Hospital in Toronto has gone on record to report that he has treated patients who received organs from China and, indeed, my own work and observations reflect this reality. Despite the government’s best efforts, Canadians are purchasing kidneys abroad.

Given the landscape of organ supply and demand presented here, I endeavour to explore what role Canadians play in the international trade in human organs, and why and how they come to realize that role. Considering that, as in many late capitalist societies,

Canada is experiencing the emergence of conditions that create a demand on medical services that surpass possible provision, and considering that the organs trade is rife with serious consequences for human rights and wellbeing, I became interested in answering the following questions: Are Canadians who are waiting for donated organs aware of the international market in human organs? And if they are aware, are they concerned about where organs come from, i.e. about the exploitation of the global underclass that is tied to their procurement?<sup>1</sup> While these initial questions provide a starting point for considering the potential “buyer” role of Canadians in desperate need of organs, most importantly, this research takes this line of inquiry a step further by asking: Under what conditions would someone participate in the market for human organs? This question is fundamental to the study of Canadians’ participation in the organs trade as it creates a space for investigating the varied ways in which individuals a) define the illness experience and treatment options available to them, b) express their awareness of alternative systems and potential concerns regarding the exploitation of others, and c) identify the role of consumer mindedness and behaviour when it comes to procuring organs, all in the hope of achieving a positive health outcome through organ transplantation.

A few notable assumptions flow from a question regarding the “conditions of participation.” First, the patient has been told by the medical system that they need a new organ or face certain death. The patient is waiting for an organ because he or she is unable to obtain that organ for themselves and thus is reliant on an institutional system for procuring and transplanting that organ. Patients in the medical system either opt to participate in the existing procurement and allocation system, or they can choose to turn

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<sup>1</sup> Exploitation is broadly defined as the utilization of impoverished populations, mainly their bodies, for fulfilling the need for organ transplants.

to the international organs market. Arguably, this second option is not for everyone, especially if one does not have the necessary finances. But there may be other factors at play when individuals weigh these options, such as their concerns about any number of issues related to international travel to purchase an organ. I, therefore, aim to investigate the decision making process that goes on in determining a chosen path of activity for procuring organs for oneself. I argue that if we can identify the conditions that need to be met that arise out of the decision making process, we can uncover the broader, structural social and cultural influences that affect decision making. It is through institutional, social and cultural knowledge as well as subjective experience that individuals come to decide which type of institution they want to provide them their organ. Ultimately, uncovering the “conditions of participation” will enable us to identify the reasons why one chooses consumption, the purchasing of the bodily products of the other, over non-consumption, receiving organs through altruistic donation, or alternatively, why non-consumption is chosen over consumption.

A question concerning the “conditions of participation” is also valuable because it allows for the identification of the boundaries of consumption. In this case, the boundary involves the body (both one’s own and another’s) as it relates to health, longevity and the likelihood of future illness. Pushing the boundaries of our desire into the realm of the body is a topic of significant debate and discussion among sociologists concerned with health, illness and the social and cultural constructions of the body in its medicalized and commercialized forms. In this case, the boundary I aim to identify is the point where a patient would say *if all of these conditions were met, then yes I would buy a kidney from someone*. Furthermore, I not only aim to identify the moment when a patient would say

“yes,” I also aim to unravel the circumstances and influences that lead patients to arrive at such a conclusion.

A review of existing literature on organs trade and transfer reveal an important division in conceptualizing potential buyer participation. As will be further explained in the next chapter, there are those who argue that Canadians, as capitalist global elites, come to see the bodies of foreign others as vessels of spare parts by virtue of their relative affluence and desire. Works in this area relate theories of the political economy of the global, medical body to the behaviours of wealthy Westerners as buyers in the international trade. That is, they present the argument that Canadians exhibit the qualities of a liberalized society where economic relations rule all facets of life and, therefore, Canadians are “consumers” first. Conversely, there are those who argue that we ought to look to our present organ transfer policy and arrangements in order to find the true values held in the highest esteem in our society. That is, systems for transferring human goods reflect particular social and cultural ideals occurring within society broadly. From such theorists we come to find that given the nature of organ transfer in Canada, Canadians support voluntarism and the willful, anonymous giving of the self through its “opt-in” strategy, therefore, we are “altruists” first. In addition to these divergent theoretical positions, there are yet others who propose that transfer systems actually contain both of these polar value sets, consumerism and altruism, whereby “donation” systems encourage the exchange of “non-monetary” gifts, yet retain their commitment to voluntary, altruistic donation. Many have sought to address this polarization through discussing alternative options for systems that they feel better reflect the liberalized medical services found in developed market economies today. Finally, there are those who seek a complete

reordering of services towards encouraging presumed consent in organ donation – or the implementation of what are called “opt-out” strategies – because it is well known for its ability to increase the supply of organs in countries where it is currently implemented. Each of these perspectives offer important ethical and ideological points for consideration, particularly when it comes to understanding the process of organ trade and transfer throughout the world. It is the aim of this thesis to provide the first in what will hopefully be a set of analyses of the “Canadian perspective” on issues of organs transfer and trade, as it seeks to provide a fresh way of thinking about the roles Canadians play in systems of unequal exchange like the market for human organs.

Viewed from a conceptual level, these varying perspectives generate a broad theoretical question that is fundamental to the preceding discussion, and to answering the research questions already presented here. That is, are we, as affluent (mainly-white) Westerners, the consumption minded, market oriented lot that some claim we are, or rather are we committed to a set of strong moral and ethical values around individual and human rights that lead to the promotion of giving and fairness over economic relationships? Are we consumers or are we altruists? These positions are obviously not a perfect dichotomy but present an ideological juxtaposition that is useful for the purposes of this work. It appears that in the literature, consumerism and altruism are understood as being in opposition to one another; economic values versus social or humanistic values. Ultimately, values play a significant role in the giving and receiving of bodily “gifts,” but which values are more dominant in the Canadian case is a point for consideration. Institutions that manage the transfer of organs provide sites of access to individuals who must face the decision to travel abroad to purchase an organ, or to sit and wait for a

donated kidney in Canada. By focusing on the organizations and institutions that are supported in Canadian society, and investigating what the users and purveyors of those organizations and institutions think of them, we can attempt to identify the Canadian position among these polar value positions. Thus, this research also aims to answer the following questions: What do people think about the current organ transfer system in Canada, and is it doing what we want and need it to do? What challenges exist in this system for people who need a kidney transplant? And finally, how effective is this system versus the alternatives?

Assuming that Canada's organ transfer system is but one type among other possible options, it is important to elaborate on the options that have been identified and discussed in the literature. First, there are market systems that involve individual rational actors buying and selling organs based on personal analyses of cost and benefit<sup>2</sup>. Second, there are free, voluntary, altruistic donation systems that rely on individuals to identify themselves as willing to donate, to "opt-in" upon death, or to become a living donor for a family member or stranger. Third, there are incentivized donation systems where individuals or families receive "non-monetary" (or hidden) rewards, such as "annual small reductions in taxes" (Healy, 2006, p. 38) for donation. Another version of this third option involves the provision of direct monetary incentives to donors and donor families, such as providing payment to living donors beyond compensation for time and resources spent. While incentivized donation is commonly referred to as a "market-based" strategy,

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<sup>2</sup> Because the buying and selling of organs is illegal throughout the world, markets remain largely underground and are considered to comprise a "black market" made possible through organized crime. Though countries, such as India, legislate for the ban of organ trade and trafficking activities, the conditions are present, such as a lack of accountability, enforcement of sanctions and deceased donor programs that allow markets to continue, particularly markets in kidneys.

it is different from a “market” identified in option one<sup>3</sup>. Fourth, there are presumed consent systems where individuals are assumed to be donors upon death, unless they identify themselves otherwise by “opting-out” from donation. Given that in Canada option two, an opt-in donation system, is the chosen supply strategy, answering these research questions will be achieved by considering what the users and purveyors of the current system think about this system in relation to their experiences with it and their knowledge of the alternatives (see Appendix A for a summary of the research questions).

Thus, the following analysis seeks to identify what role Canadians play in the international trade in human organs, and how and why that role is realized, assuming that the available and accepted form of organ transfer presents the context within which patients make the decision to either travel abroad or stay and wait for a donated organ in Canada. This study focuses on literature from a range of social science disciplines in order to provide a broad context for investigating processes of organ transfer and trade. It will also present an analysis of data collected through semi-structured interviews with patients and their caregivers who are involved in a kidney transplant program in southern Ontario. Such data provide the context “on the ground” and is based on the lived experiences of patients and medical professionals. They also provide additional insights for this analysis that stem from administrative knowledge, particularly regarding the organization of organ transfer within the province. The next chapter provides a discussion of relevant theories and concepts required to identify how and why Canadians come to

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<sup>3</sup> Incentivized donation systems are often referred to as “market-based” in that they contain features of markets, notably they involve a more or less direct transfer of funds to “donors”, whether they are paid by the government or by a buyer, which is regulated to some degree by the government, such as in Iran.

participate in the international trade in human organs, and the values that influence their decision.

Thus, Chapter 2 provides an overview of the theoretical framework and literature reviewed that help to guide and inform the analysis undertaken in this thesis. It includes a discussion of major theoretical insights involving meaning-centred research in health and health care, as well as how to approach issues of organ transfer and trade from a political economy perspective. In terms of the relevant literature, it discusses important academic as well as substantive materials that aim to provide a context for exploring the role of values and institutions in patient decision making when it comes to procuring needed organs.

Chapter 3 discusses the methods used to investigate the research questions presented above as well as a description of the population under investigation. It demonstrates how qualitative, ethnographic methods were used in collecting data for this study.

Chapter 4 presents the main findings of this study capturing both relevant contextual information as well as insights into patient and medical professional perspectives on organs transfer and trade. This section highlights perspectives in regards to the experience of waiting on dialysis for a donated kidney as well as perspectives on the various types of transfer systems mentioned above.

Chapter 5 connects the findings of this study with the literature presented in Chapter 2 and elaborates on the major implications of the “Canadian position” in the consumerism-altruism divide. It engages both the contributions of academics in the field of health and health care and organs trade, as well as the contributions provided by the

study participants. Thus, it aims to answer the main theoretical question presented in this study.

Finally, Chapter 6 presents an overall conclusion for this analysis and identifies potential limitations of the present study, as well as areas requiring further investigation.

## **CHAPTER 2: Theoretical Framework and Literature Review**

Canadians requiring organ transplants, particularly kidney transplants, make decisions regarding the management of their care; including how and where they will procure their transplant. These decisions are made within a complex social, cultural, political and economic nexus. The following theoretical framework and literature review help to develop an analysis of how these components factor into patients' decisions to participate or not participate in the market for human organs. This chapter begins with a discussion of the theoretical framework that informs the work undertaken in this study. The framework combines two approaches: the sociology of health and illness behaviour, specifically meaning-centred approaches, and political economy of health and health care. The literature review that follows is informed by this framework, and seeks to provide conceptual as well as substantive evidence to help answer the research questions. The literature review is predominantly concerned with: explaining the historical development of Canada's health care system; locating the body of impoverished others in a global context, and the role of buyers in markets for human organs; identifying the dominant social values in systems for organizing the transfer of human goods, including a discussion of the types of organ transfer systems that are available in the world; and finally, identifying where Canada fits within this set of transfer system models and ideologies. Overall, the goal of this chapter is to provide a review of relevant works to begin to answer the main theoretical question of this thesis and that is, where do Canadians fit within the polar camps of consumerism and altruism when it comes to procuring much needed organs.

## **Theoretical Framework**

The following is a discussion of two theoretical orientations, which together provide a useful framework for considering the role of buyers in the international market for human organs, and the role of institutions in creating or mitigating the conditions for participation. First, I draw on the sociology of health and illness behaviour and more specifically take a *meaning-centered* or “*meaning-seeking*” approach as it allows researchers to engage in structural debates while at the same time making important individual lived experience. Second, I draw on the works of Canadian sociologists in the field of health and health care, particularly those who take a *political economy approach* to investigating health and health care. These authors attempt to situate the present context of Canada’s medical system in its political, economic and social history. That is, they provide the basis for discussions concerning the broader social and institutional order and its role in shaping the health care environment in Canada. Importantly, these authors emphasize the individual within this order, and how relations between individuals are shaped by struggles for power and profit. This framework provides the basis upon which to analyze, explain and challenge the Canadian role in the international trade in human organs, and how institutions create or mitigate the conditions that make participation possible and desirable.

### ***Sociology of Health and Illness Behaviour: Taking a Meaning-Centred or “Meaning-Seeking” Approach***

This study draws on the tradition of the sociology of health and illness behaviour, which Coburn and Eakin (1998) define as a sub-theory of the broader field of the

sociology of health. As the name suggests, this theoretical tradition aims to unravel the ways in which people “perceive, understand and respond to health and illness related states or events” (p. 623). For example, health behaviour refers to the ways in which people define health and that which threatens it, as well as the efforts they make to protect it. Illness behaviour, however, refers to one’s interpretation of signs (e.g. what it means to be “sick”), one’s experiences entering and interacting with the health care system and the social processes involved in disability and death (p. 623). Theories of health and illness behaviour, then, are focused on examining health and illness as social products.

Within the health and illness behaviour tradition there are two ideological and methodological perspectives. Those who seek to identify how the structure of social life impacts health take a “structure-centred” (Coburn & Eakin, 1998) or “structure-seeking” (Pearlin, 1992) approach. For example, this type of work might involve a research team who surveys patients in a mental health clinic to determine the impact of socio-economic status on mental health, whereby socio-economic status acts as one quantitative variable from which to draw inferential data regarding patients as an aggregated group (Pearlin, 1992). Thus, this approach seeks to compare groups across variables that are taken as truths and are thought to be relatively consistent over time. Conversely, those who seek to identify the meaning of social life and the impact that meanings have on health, take a “meaning-centred” or “meaning-seeking” approach. For example, a researcher may conduct observational research and semi-structured interviews, and experiences deep immersion in the qualitative data throughout the data collection and analysis process. This approach is focused on providing the most accurate representation of the actual social realities of people. Importantly, Pearlin (1992) states that “however abstract and

imprecise these terms [structure-seeking and meaning-seeking] are [as concrete groups], they bring into focus and help to explain an adversarial alignment that seems to be one of the major axes along which medical sociologists are divided” (p. 2). Perhaps unsurprisingly, then, researchers occupying either one of these camps, oppose the value of the work of the other. Structure seekers point to the small sample size and inability to generalize and compare the results obtained by meaning seekers, while meaning seekers criticize structure seekers for transforming people into numbers and leaving behind the “humanistic roots of sociology” in order to “emulate other sciences” (p. 6). Further, research aimed at investigating structural features is thought to present testable and, therefore, reliable results, whereas research aimed at investigating meanings is thought to be valuable in exploring, elaborating and bringing or moving forward new ideas. Importantly, these approaches represent particular understandings of the role of structure and agency in people’s lives.

Coburn and Eakin (1998) explain that the majority of research done in the area of health and illness behaviour in Canada is structure-centred, which they argue is due to the influence of the health care system in the framing of research. For example, research within the health care system aims to identify who uses medical services and why as well as barriers to compliance. However, meaning-centred research, which bases its investigation on the perspectives of those “doing the behaving,” has been growing in the sociological literature. It has also become increasingly popular for sociologists to blur the lines dividing these camps. In particular, researchers have sought to investigate the macro-structural factors involved in health and illness behaviour, through the analysis of micro-subjective experiences. There are a few notable examples of research that has been

undertaken which cut across the dividing lines that separate these camps, usually beginning with qualitative, interpretive, meaning-centred approaches; that is, studies that seek to explicate the structural through interpretative means are still considered meaning-centered. For example, Anderson, Blue and Lau (1991) studied women with diabetes and the restructuring of their lives that occurred post-diagnosis. They analyzed Chinese immigrant and Anglo-Canadian women's descriptions of their beliefs about illness, the impact of their illness on their social lives and their experiences interacting with health professionals. Their goal was to explain how illness is "constructed in a complex social, political and economic nexus" (p. 101). The researchers interviewed 27 women over a two year period and developed detailed socio-demographic profiles throughout. They found that the Chinese women, who they defined as working class as they tended to be factory workers, found it more difficult to manage their illness than the Anglo-Canadian women. They argue that this was due to the Chinese women's inability to restructure their work lives around their new health requirements, and access resources and knowledges that were available to the Anglo-Canadian women. Further, the Anglo-Canadian women, who were defined as middle class as they tended to work in administrative jobs, were better able to put the management of their disease at the forefront of their lives, such as by changing jobs to accommodate the changes in their health routine. The Anglo-Canadian women, then, had an easier time coping with their illness; they also tended to have better health. The authors argue that the ways in which women come to understand, cope with and manage their illness depends upon their socio-economic status and access to resources to improve their ability to provide self-care, rather than merely their supposed cultural differences. Importantly, Anderson et al. provide an example of research that is

based on the following assumption: “the vocabularies of the larger social organization are reproduced in micro-level interactions between women and health professionals through a set of ideologies that structure health care delivery” (p. 102). That is, the perspectives of those experiencing illness contain within them the interplay of both personal and social structural factors that influence the ways in which health and illness are managed, and how patients behave given the opportunities and constraints of their environments.

Thus, research in health and illness behaviour involves studies that capture the roles of both agency and structure in regards to whatever particular issue is under investigation. This study, then, methodologically speaking, borrows from studies like Anderson et al.’s by taking a meaning-centered approach to health and illness behaviour, in the context of waiting for a donated kidney. Upon becoming ill, patients with renal failure must make choices about their treatments, such as deciding between undergoing dialysis in the hospital or in the home or determining how best to manage the lifestyle changes that come with a diagnosis of renal failure. They must also face a wait of up to six years for their transplant, and purchasing a kidney rather than waiting for a donated one is an option for many of them. How and why patients come to realize their role as potential organ buyer is a major component of this study. The current donation system does not support or allow the commodification of the body; one cannot put a price on life in Canada. Canadians, however, are buying organs abroad. As such, there is a need to address both the personal as well as the social influences that impact decision making when it comes to viewing the bodies of foreign others as sites for organ harvesting. The structural component of this work, then, includes developing an understanding of social, political and economic factors that shape the ways in which individuals interact with one

another in the clinical environment and in society both in Canada and in a broader global context. The personal or subjective component of this work involves the interpretation of these structural factors, in combination with lived experience. Thus, this analysis will take a meaning-centred approach that addresses both agency and structure in order to identify the dominant values that influence patients' decisions to travel abroad or stay and wait for a donated kidney in Canada. The next subsection deals with the second theoretical approach adopted by this study, which is a critical political economy of health approach. This provides a starting point for considering the political and economic nature of health care, as well as the dominant values that are maintained through its organization.

### ***Political Economy of Health and Health Care***

In their book *Changing Canada: Political Economy as Transformation*, Clement and Vosko (2003) define what they call “the new Canadian political economy” as follows: “it seeks to abandon the common sense-view that certain things (e.g. capital or markets) and social and economic systems (e.g. capitalism) are irreducible” rather, they are “*always* in process or flux” (xiii); it “aims to trouble and challenge conventional ways of framing issues, in particular, in the present era, the neoliberal paradigm and its project” (xiii); “it recognizes how the strategic choices of social actors are limited by circumstance, time and space” (xv); it “does not pretend to be value-free” (xix); and, it understands that the “objects and subjects of study [that are] taken to be fixed or static and unproblematic in the empiricist and positivist traditions of political science and neoclassical economics” (xiii) are contradictory, creating spaces for transformation and positive social change. Political economy emphasizes the historical nature of social

change, questions the covert motivations found in political action, and seeks to challenge the taken for granted ways in which individuals engage with, study, and understand the world. More specifically, political economy takes aim at capitalism and the neo-liberal agenda, and the impact that structural reformations, globalization and commoditization have had on the public realm, including workplaces and labour markets, as well as the private realm, including individuals, families and households.

Research in political economy covers a range of issues, including health, education, manufacturing, work, the state, law, foreign policy and sports, just to name some. It is primarily focused on transformations among groups in civil society, whereby citizens actively engage with and resist political and institutional forces that create problems in their lives, such as difficult and intensified working conditions or gender, race and class discrimination. According to Clement and Vosko (2003), a strength of political economy is its engagement with a range of issues that cut across disciplinary boundaries, while maintaining its exploration of the tensions and contradictions found everywhere in order to bring about social change. For example, in their book *Wasting Away: The Undermining of Canadian Health Care*, Armstrong and Armstrong (2003) take a feminist political economy perspective towards state provided health care in Canada. They focus on the historical development of Canadian Medicare, particularly the influence of conservative ideologies in shaping the care environment, and they identify the tensions that new policies in health have created for workers and families. Of note are the gaps that have appeared in services which generate a need for care in the home or community, and their impact on the lives of women who tend to fill these gaps. They note that the struggle over power and resources in the context for Canadian health care is likely

due to the contradiction of having both public and private interests involved. Part of their work, then, is to provide solutions for transformation. Thus, “political economy, through its understanding of contradiction and change, can serve as a transformative tool in both scholarly work and action” (Clement & Vosko, 2003, p. xv).

It is important to consider that a political economy of health is different, though not necessarily separate from a political economy of health care, particularly because this study deals with both, and it is common for writers to conflate the two (see Coburn 2006). The political economy of health considers how the organization and distribution of health services ensure or threaten the health of a society, shape the ways in which individuals define health and illness and how these states are obtained, and make explicit to the extent to which individuals are accountable for their own health or illness (White, 2009). The political economy of health, then, engages tensions that are found in an insistence on a medical model that is individualistic and does not necessarily improve health all the time and for everyone (White, 2009). A political economy of health care, however, involves a consideration of systems and institutions of care and how changes within them have unintentional consequences that impact the social and physical environments of both workers and patients (see Armstrong & Armstrong, 2003). Thus, a political economy of health care tends to focus concern at the level of policy and contradictions between that which is intended by policy makers, and that which actually happens “on the ground” (Armstrong & Armstrong, 2003). Arguably, there is a great deal of overlap between these issues, and this is because both place an emphasis on the context of the overall structure of the health care system, as well as the social and physical environments within which citizens engage with the system.

Building on this discussion, Coburn (2006) explains that approaching health and health care from a political economy perspective is valuable in its appreciation for the complexity of social phenomena within and beyond the care environment, and within and beyond nation states. According to Coburn, political economists ask the following questions regarding health and health care:

Why do some people, groups, nations or groups of nations have better health than others? Why is it that some groups or societies have different kinds of health care systems than others? How much inequality in health and access to health care is there and why are there these inequalities? What is defined as healthy and what is defined as sick in particular kinds of society and what do people do about these states? How do all these things vary historically and across nations or societies?  
(p. 59)

Thus, such an approach also allows us to consider the differences between nations, their health and health care systems and ways of defining each and, more importantly, allows us to question how these differences came to be and why they exist. Coburn argues that what is unique about the political economy approach to health is its focus on “the link between health and the economic, political and social life of different people, regions, or societies” (p. 59).

Further, Coburn (2006) explains that taking a materialist approach to the political economy of health and health care emphasizes the impact of material conditions on behaviour. That is, taking a materialist approach involves “viewing ideas and institutions as emerging from how a society organizes production, and uses such concepts as mode of production and class” (p. 60). This approach is useful in that it provides a starting point

for considering not only how capitalism and the dominant ideologies which support it (e.g. neo-liberalism) affect individual behaviour within a particular nation, but also how that behaviour is similarly influenced by capitalist relations between nations. That is, a materialist approach allows us to question how relations of production between first world organ buyers and third world organ sellers play out in a broader global political economy. According to a neo-liberal ideology, individual buyers and sellers ought to be able to participate in an exchange of goods free from intrusion and restriction on the part of governments and their institutions. Given that capitalism is the global standard, we can understand how individuals perceive this form of exchange as both common and appropriate. However, what such an exchange ignores are important differences that exist between buyers and sellers, one of which is their country of origin, another being their relationship to capital. To say that organ buyers are typically middle to upper class (white, wealthy and western), and that sellers are lower class (non-white, poor and southern or eastern) is perhaps an oversimplification; however, this does appear to be the most common arrangement. Taking a materialist approach to conceptualizing political economy helps us to better understand that individual actors exist within a particular type of national and global context, which in many ways dictates how they come to relate to one another.

This study takes a political economy approach and it is, therefore, my goal to bring to light how Canada's political economy impacts the health and experiences of those involved in organ transplant, and to identify and challenge the ways that individuals understand their relationship to global others. Overall, this discussion of a political economy of health is meant to set the stage for considering the case of Canada and the

dominant political, economic and social influences that shape the formation of health and health care provision, organ transfer systems and patients' decisions to obtain kidney transplants.

### ***Conclusion***

Recall Anderson et al.'s (1991) study on the life restructuring and health management of Anglo-Canadian and Chinese immigrant women following a diagnosis of diabetes. Their study provides an example of research that combines a meaning-centred approach with an analysis and discussion of issues relevant to political economy. Based on their analysis of interpretative, qualitative data, they discuss how the structural arrangement of state sponsored medical treatment expresses particular ideological views, which not all users of the system are able to adopt or understand. Mainly, they highlight the demand for 'self-care' in "mainstream Western society" which they argue "is not an isolated ideology, but is consistent with... 'the basic tenants of bourgeois individualism and freedom of choice'" (p. 110), and they locate immigrant women in terms of their relationship to such mainstream ideologies. The authors state:

Dominant ideologies [such as 'self care']...organize the expectations that practitioners have of patients, but also enable patients to incorporate the professional corpus of knowledge, and to meet the expectations of professionals... 'The state' then, is not an apparatus that functions apart from individuals and institutions...to produce and maintain ideologies such as self-care, but the discourse of daily life including the professional discourse are instances of how the state works – there is a dialectical relationship amongst the different

arenas of health care; patients, practitioners, and policy makers, through which ideas are constructed and maintained. (p. 111)

Anderson et al. argue that because immigrant women were typically of a low economic status lacked the level of education found among the Canada born women, and had a poor grasp of the English language, they were excluded from this ideological discourse and the appropriation of professional knowledges that may have improved their ability to provide self-care. Thus, these authors were able to draw on ideas about the influence of ideologies circulating within the state apparatus of health care in order to explain the difference in patients' success or struggle to provide self-care.

Arguably, Anderson et al. (1991) provide a valuable example of how to go about connecting structure and meaning in sociological research. While I do not endeavor to identify the impact of the socio-economic status of patients on their ability to manage their illness, I do aim to draw connections between the complex social, political and economic factors that inform and influence patients' decisions to obtain the required medical service of a kidney transplant. It is my contention that these factors are expressed through value statements, such as claiming that particular practices are "right" or "wrong." This study also assumes that patients hold the position of affluence in the relationship between organ buyers and sellers, and, therefore, it does not involve a comparison between participant groups on socio-economic indicators. Overall, Andersen et al.'s analysis of the role of access to discourse and ideology within and outside of the care environment in patient self-care is compelling. They present one example of how research can not only bridge the divide between structure and meaning, but also bring to light important points for discussions relevant to the political economy literature.

In terms of a theoretical framework, then, this study combines a meaning-centered approach with a political economy of health and health care approach in order to investigate the role of Canadians as buyers in the international market for human organs and how institutions that organize organ transfer influence patients' decisions to travel abroad to buy organs. This approach assumes that Canada's, as well as the global, political economy shape the ways in which individuals requiring transplant make procurement decisions, which are similarly influenced by personal, lived experience. Thus, this study assumes that the clinical environment in which patients requiring transplant find themselves is a microcosm of the larger institution of organ transfer specifically, and health care generally, which are political and economic in nature. Patient experiences as well as the experiences of those who work in the clinic are thus both highly relevant to an analysis of organ transfer and trade in and outside of Canada.

The broad theoretical question of this study is "are we consumers or are we altruists?" when it comes to procuring organs through consuming the bodies of others or waiting for a donor, respectively. This framework provides a basis upon which we can seek to answer this question, by taking both a meaning-centered and political economy approach. The following literature review seeks to engage this main research question through a discussion of works relevant to an analysis of the dominant values and ideologies circulating within Canadian society, its health care and organ transfer systems.

### **Literature Review**

The following literature review is divided into five subsections. The first subsection is entitled *The Political Economy of Health Care in Canada* and it highlights

the historical political, economic and social shifts in the last 70 years in Canada that have led to the organization of care today. The next subsection, entitled *The Political Economy of the Global, Medical Body*, expands on a political economy approach to bring the body of foreign others and the trade in human organs into the discussion. This includes conceptualizations of the body as object, as a site of production, as a commodity, and as a globalized exchange good. Importantly, it also provides evidence to support the argument that Canadians are indeed “consumers” in the global economy of the body. The third subsection, *Welfare State Medicine and the Case for Altruism*, provides a discussion of the role of social values in the development of institutions that organize the procurement of human products. The fourth subsection, *Canada: Organ Transfer Through “Opt-in” Donation*, discusses Canada’s opt-in organ transfer system and provides counter evidence to the claim that Canadians are “consumers” first, as they support an altruistic organ donation system. Assuming that Canadians may fall somewhere in the middle of the consumer-altruism divide, the last subsection, *Addressing the Consumer-Altruist Polarization: Incentivized Donation and “Opt-out,”* provides a discussion of alternative strategies for arranging organ transfer. Thus, this literature review is designed to bring together relevant ideas regarding the ways in people understand and engage with the bodies of foreign others, the organization of organ transfer and the dominant ideologies that underlie the implementation of different forms of transfer systems.

### ***The Political Economy of Health Care in Canada***

*“Medicine must be seen as part of the social structure. It is the product of any given social environment. Every social structure has an economic base, and in Canada this*

*economic base is called capitalism, avowedly founded on individualism, competition and private profit...Medicine is a typical, loosely organized, basically individualistic industry in this 'catch as catch can' capitalistic system operating as a monopoly on a private profit basis" (Allan and Gordon, 2009, p. 129)*

Allan and Gordon's (2009) quote highlights some particularly important qualities of the Canadian health care system, emphasizing the roles of economics and profit making in the ways individuals organize themselves around the provision of health services. Missing from their description, however, are a few other characteristics that are worth mentioning. Access to basic health care services is a highly valued social right in Canada; indeed, access to medicine and allopathic care is deemed to be a human right similar to voting and having access to public education (Clarke, 2004). Clarke (2004) states that in Canada, access to health services that significantly improve the quality and quantity of life of an individual is a right and inaccessibility is, therefore, an issue of social justice (p. 239-254). Living free from pain and being able to engage in activities important for personal growth or for the wellbeing of one's family are rights that Canadians believe they deserve, and ought to be upheld by governments. As Wiktorowicz (2006) states, values are reflected in legislation, and thereby shape the form that social policy takes, especially in terms of health care. Canada's health care system is comprised of a well-engrained network of institutions designed to provide the kind and quality of care that all citizens expect. The accepted status of health care as a universal right leads to intense public and political scrutiny when reform to the system is discussed in parliament. Thus, health care in Canada is a social institution that is supported by the public broadly, and in many ways reflects the needs of those it serves.

As a state-sponsored system, medicine also is intimately tied to other areas of state intervention, particularly economic management. The absence of health for a country and for individuals is seen as an impediment not only to social reproduction, but to production, as ill health decreases individual labour power and consumption as a result of reduced income. Said differently, the provision of health services through social spending is one factor that is included in a range of programs designed to sustain a healthy and productive country<sup>4</sup>. In the instance of ill health, and thus low worker productivity, the medical system ensures that the physical reproduction of individuals will take place so that people remain valuable assets to society. Within medicine, not only is there an emphasis on ensuring the “return to work” and the prolongation of the use value of individuals, but rehabilitation also occurs through the consumption of ‘healing’ commodities (Clarke, 2004). Thus, health care is also an industry. Health care systems then require a careful balance of funds and fees whereby working people can receive the benefits of health services at no or a reasonable cost, but at the same time, policy makers and administrators must satisfy the interests of profit-minded suppliers and professionals. As Allen and Gordon (2009) explain, the health care system was developed in and is part of a liberal capitalist state and, thus, is significantly influenced by and has a history rooted in Canada’s political economy.

It is important to consider how it came to be that Canada has a state sponsored health care system within a capitalist society, and how it has or has not lived up to its promise of a socialized system. Swartz (1998) explains that Canada’s welfare state developed out of the economic crisis following the post-WWII boom. Broadly speaking,

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<sup>4</sup> Spending typically refers to federal transfer payments in the form of pensions, health expenditures, income transfers and investments (Bryant, 2006).

it arose as a result of the vagaries of capitalism, such that governments became responsible for providing particular social needs, such as health and education, that private owners were not willing or able to provide to all individuals. States that adopted the new Keynesian approach<sup>5</sup> came to rely on marginal extractions from public income to provide such welfare services. Swartz argues that because welfare states rely on public income that is earned through labour outside of the home, welfare states are not inimical to capitalism and private interests, but rather, are important for maintaining the status-quo, capital accumulation. The relationship between welfare regimes and capitalism then is a complex one, and is exemplified in a discussion of the development of health insurance in Canada.

Swartz (1998) argues that health care in Canada is a mix of public and private interests, which has been the norm since the implementation of provincial health insurance schemes beginning in the 1950s. The discussion of national health insurance began in Canadian parliament following an influx of mainly working-class political representation in the western provinces, such as the Co-operative Commonwealth Federation, which later became the New Democratic Party. The issue brought forward was that if working conditions make workers sick, someone has to provide for their care. In 1957 the Pearson-led Liberal federal government introduced the *Hospital Insurance and Diagnostic Services Act*, which committed the federal government to sharing the costs of provincial health insurance plans. The *Medicare Act* (Bill C227) 1966 outlined

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<sup>5</sup> During the Great Depression of the 1930's, Keynes witnessed that decisions being made in the private sector led to poor macroeconomic outcomes. He argued that there ought to be a sustained role of the public sector and fiscal policy actions to help smooth the business cycle, such that through public sector interventions, the impact of economic booms and busts on nation states can be lessened (for a discussion of the main tenants of Keynesian economics, see Bade, Parkin & Lyons, 2004, p. 330, 367-368).

the criteria upon which federal funding would be based: “namely the plan be universal, cover all physicians services, be financially administered on a public, non-profit basis and portable from province to province” (Swartz, 1998, p. 538). By 1972, when Ontario joined the other provinces in implementing the Act, the socialist intention for Canada’s public insurance plans was lost, as Swartz asserts “what was in place...was anything but socialized medicine” (p. 538). The legislation of national and provincial health insurance schemes was not designed to allow public control over the supply of medicine or the activities of drug corporations. Rather, what was socialized was the cost of hospital care. Health insurance was and is presently primarily concerned with personal health care, the provision of services from a medical professional to an individual who must separately obtain pharmaceuticals from a supplier. Thus, what is socialized is the service (i.e. practitioners charging for the services they provide), rather than the production (i.e. how those services are organized and made available), and delivery of the service (i.e. the kinds of services offered). In this way, the state transfers public funds to private care providers and drug companies, rather than presiding over the development and administration of care. The state does not challenge the autonomy of care and drug providers, and supports their freedom to operate on a for-profit basis. Thus, Canada’s health care system is a mix of both public and private interests as citizens pay into and expect a particular standard of service that care providers do not necessarily have to abide by. Swartz explains that this has been the arrangement in Canadian health care since the introduction of provincial health insurance schemes.

Swartz (1998) goes on to argue that the implementation of health insurance in Canada did not necessarily make health care more accessible, which was initially an

important requirement for the working class and their political representatives. Because payments were awarded for services to private businessmen (e.g. physicians), there has never been an incentive for physicians to move out of large urban areas, no requirement that they hold office hours outside of the regular 9-5 work day, and no responsibility to provide transportation or child care services, all of which would make care more accessible to the working class. According to Swartz, the issue of access to health care in Canada stems from the private nature of medical provision and the absence of a truly socialized system. Thus, despite its goal of providing fair, equitable and universal care for all, health insurance, from the beginning, had little impact on class-based health inequalities in Canada.

By the late 1970's, the cost of health care in Canada was growing and the welfare state came under attack by a new conservative agenda, which supported neo-liberal policies and led to the limiting of federal funds in health care (Swartz, 1998). This new agenda supported a doctrine that placed the blame of ill health squarely on the individual. This was followed by a number of restrictions at the level of hospitals, such as reducing the number of beds and staff and freezing wages. This caused an upheaval in the medical community as restrictions on fees were seen as an affront to previously enjoyed freedoms. As a result, medical professionals began charging user fees to patients to cover the difference between the more restrictive government provided fee schedule and rates they believed were deserved. Governments across the country ignored and thereby allowed the practice of charging user fees. A subsequent resurgence of the Liberal political party under Trudeau led to the implementation of the *Canada Health Act* (the most recently implemented Act) 1984 which eliminated user fees and extra billing. This was meant to

acknowledge that additional fees acted as barriers to accessing health care. Still, at that point, the model had been created. Canada's health care system today continues to be a liberalized fee-for-service system, for which the government transfers public funds to pay for specific and limited services, without concern for accessibility or the affordability of services that are not covered. The development and provision of services remain mainly within the private sector, and the cost of health care in Canada is one of the highest in the developed world.

The form of health insurance and provision of care in Canada also explains health care's rapid expansion in the decades following the 1984 Act. The consequences of this expansion have been noted in the literature. Swartz (1998) notes that a problematic development in the liberalized fee-for-service system is the "overproduction of curative services" (p. 543) and the economic incentive for physicians to see more patients, giving less and less time to each. While medical professionals individually are not in control of the forces that create this situation, they maintain it nonetheless. Unfortunately, the intensification of care has led to increasing worker fatigue and less thorough care. While the system continues to grow, its quality is threatened. Swartz cogently argues "the fragmentation inherent in a system characterized by individualism and competition defies proper service delivery" (p. 543). However, health care continues to grow in this fashion, with an overproduction of services at all levels of care, resulting in mounting hospital and clinic deficits across the country.

The appropriateness and effectiveness of liberal health care systems have been challenged by a number of authorities on the subject. For example, Armstrong (2003) highlights the shift in the production of care delivery towards meeting "consumer" or

“client” demands in market economies. Others explain that markets depend on consumers to make rational consumption choices, but patients, who are treated as “clients,” may not always be capable of making decisions about their care (Armstrong, Bourgeault, Choinière, Mykhalovskiy & White, 1999). That is, not all patients are capable of becoming a specialist in their own health. Thus, Armstrong (2003) argues that given the inability of the private sector to provide appropriate medical services, many Western health care systems maintain specific social justice oriented programs that help to ensure patients are able to access services. Still, there is an overall tendency to support private interests in the formation and organization of programs.

Thus, the history of Canada’s liberal welfare state health care system is marked by the ebbs and flow of ideas that are reflected in political change. Coburn (2006) explains that similar ideological shifts have also circulated the globe and impacted the formation of health care in the developed and developing world. Notably, he compares the development of health care in Canada to that of other developed nations to explain the influence that globalization and the spread of neo-liberalism have had on care provision. In response to the degradation of state provided health services that global neo-liberal economic reform has caused, nations have developed unique mixes of services, which are supported by policies and institutions. Importantly, he notes that class composition and class power are significant indicators of the form that a health system will take. For example, welfare regimes such as those found today in Canada, the United States, the United Kingdom and the Scandinavian countries “can be categorized according to the extent to which they decommodify citizens’ relationships to the market” (p. 65), that is, the extent to which citizens are able to live independently from the labour market and yet

are able to achieve a decent standard of living. The decommodification of citizens' relationships to the market is accomplished by providing alternatives to labour market participation, such as through the provision of unemployment insurance and pensions. He explains that social democratic welfare states have the greatest decommodification, including Sweden, Norway and Finland, while liberal welfare states are the most "market dependent and emphasize means and income testing" (p. 65), including the United States, the United Kingdom and Canada<sup>6</sup>. In the liberal welfare state of Canada, health care is provided on a basic security model, which is an insurance system designed to cover some of the costs of care, but only for basic services. Despite the working-class campaigning that led to a commitment to universal health care in Canada, at this present moment in Canadian history, big business and politics continue to undermine the quality and effectiveness of the system. As a result of the influence of private interest, quality suffers. For example, long wait times and geographic disparities are common complaints (Armstrong & Armstrong, 2003). Thus, dominant political and economic ideologies that have become prevalent all over the world have shaped Canadian health care in the interest of capital and profit.

Today, Canadian health care continues to be funded through a system of taxation and administered by private institutions. The system includes the state as a rationing funding body that provides transfer payments to the provinces and territories to ensure the continued functioning of their insurance schemes and health care services broadly.

Provinces and territories then transfer payments to private service providers (i.e. fee-for-

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<sup>6</sup> There is also an "intermediate group" called the "conservative, corporatist, or familist welfare states", which Coburn (2006) claims are "characterized by class and status-based insurance schemes and a heavy reliance on the family to provide support" (p. 65). These states include France, Germany and Italy.

service professionals and hospitals). Because of its role as funder, the state is a powerful and important manager of the health care system, yet it is kept at arms-length to professional associations and administrative boards of institutions of care. These bodies hold a significant amount of power in that they are able to mitigate the flow of funds by setting their own fees and allocating funds based on interests and technologies (Freidson, 1970). For example, the Ontario Medical Association, which represents the “political, clinical and economic interests of the province's medical profession,” negotiates physicians’ fees with the provincial Ministry of Health and Long Term Care; however, as the main body of experts on the formation of policy surrounding physician and patient interests, such associations are essentially able to determine their own fee schedules. Because of this organization of health care funding, when inefficiencies arise, change is slow. The position of power and authority that medical associations hold serves to disrupt change and often leads to backlash within the medical community when changes are proposed. Ultimately, the costs of inefficiency, which may be seen as the result of misallocated funds, are downloaded onto both health care workers and patients (Curtin, 1999). Thus, Canada’s state-sponsored system of health care is complicated by the varying interests that guide its organization, and, in particular, there is a strong continuing role of ‘medicine as industry’ that serves to create challenges in providing quality services for all.

To summarize, access to basic health care is deemed to be a human right in Canada. The history of Canada’s health care system – its reforms, challenges and successes – is marked by shifting perceptions in what governments ought to provide when it comes to health services. Universal health insurance was a major step towards

acknowledging the social democratic rights of citizens, and forever solidified the formation of and political commitment toward a universal health care system. However, some argue that since the late 1970's there has been a systematic dismantling of the system that was far from fully democratic to begin with (Armstrong & Armstrong, 2003). Indeed, from the beginning, private interests have been represented in Canadian health care, particularly in the form of fee-for-service provision (Swartz, 1998). This insistence on private profit making within a national, state-sponsored system triggered not only the rapid expansion of health care services, driving hospitals and clinics and the nation into debt, but also the simultaneous reduction in quality and access. Furthermore, the power of professional associations to set their own fees marks a significant conflict of interest in a system funded through public contributions. Today, Canada's liberal welfare state is committed to providing support for particular services, under particular circumstances, and is far from a true commitment to a social justice model. Still, the universality of care in Canada is an important and arguably defining quality of "what it is to be Canadian" for many citizens (Coburn, 2006). Medicine remains an industry in Canada, and health care remains a system that is a mix of public and private interest.

This section discussed the formation of Canadian health care and the specific social, economic and political influences that have marked shifts in its development over the last 70 years. This section thus allows us to locate the target groups of this analysis, patients and medical professionals involved in kidney transplant, within the broader structural context of Canadian health care and society generally. Additionally, it is important to consider that Canadians are not only located within their particular national social order, but they are located within a global one as well. Thus, in addition to

considering the political economy of health care in Canada as a base for the investigation undertaken in this study, it is equally important to consider the political economy within which Canadians engage as global citizens. Specifically, I refer to the practice of Canadian participation in the international organ trade, and how values and interests influence that participation. The following section discusses the political economy of the global, medical body, whereby the bodies of global others become sites of organ production, and bodies become attached to particular meanings and qualities that promote and maintain particular political and economic arrangements. It addresses a number of important considerations for identifying how and why Canadians participate in the trade, and how values shape the nature of trade between the first and third world.

### ***The Political Economy of the Global, Medical Body***

The international trade in human organs is perhaps one of the most disturbing features of the current global capitalist era and recognition of its existence continues to grow. Today, one can pick up a news article in practically any nation and become part of a conversation about organ stealing, trafficking, selling or brokering. This is partly the result of the work of social scientists interested in uncovering the dangerous and complex world of the global organs trade. In particular, Scheper-Hughes, an American critical medical anthropologist, has dedicated a significant portion of her career to studying the characteristics and social position of those who sell organs or fall victim to organ theft and challenging the motives of those who buy organs from such individuals. Her ethnographic field work spans the globe. She has uncovered vast criminal networks that include brokers, transportation service providers, hotel and hospital staff, surgical teams and a number of other “middle men” who connect desperate buyers and sellers across vast

distances. Scheper-Hughes' work and other similar efforts made by concerned global citizens have been effective in spreading awareness about this dangerous and exploitative trade.

Having a human rights focus, Scheper-Hughes' work presents a very bleak picture at the dawn of 'millennial capitalism.' As she explains, organs trafficking and trade prey on the most impoverished, marginalized and disadvantaged people around the world, with the benefit, life itself, accruing to the wealthy. Though "trade" is a considerable component of the organs market, organs "trafficking" is also common and is related to human trafficking broadly. Indeed, in the past, the World Health Organization categorized organ trade and trafficking as falling under the broader activity of trafficking in people, such that it was understood that men, women and children are not only exploited for their labour or their sex, but also for their organs. A common term used in describing the act of trafficking human organs is biopiracy. This term is generally defined as the practice of stealing organs from unwilling, non-consenting individuals. For example, a young Brazilian mother undergoing a routine surgery for ovarian cyst removal wakes up to learn that one of her kidneys has mysteriously "gone missing" (Scheper-Hughes, 2002). Though the truth of "organ theft legends" are contested (Campion Vincent, 2005), the evidence is compelling; firsthand accounts and interviews with those who have experienced such acts are difficult to ignore.

Beyond threats to human rights, the trade is further problematized when one considers the role of middle men in organizing exchange. The organization of cross-border organ trade is complex and expensive. Scheper-Hughes (2003) explains:

[It requires] extensive and expert teamwork among medical professionals, from lab technicians to nursing staff, to nephrologists and blood and tissue laboratories, to the surgical teams who operate in tandem. Surgical units must be rented, passport, visas and air travel arranged, and immigration officials to be dealt with. The entire process is facilitated by a new international network of body Mafia ranging from sleazy (and sometimes armed and dangerous) underworld ‘kidney hunters of Istanbul and Cesenau, Moldova, to the sophisticated but clandestine ‘medical tourism’ bureau in Tel Aviv and Manila. (p. 214)

There are a number of people involved in kidney trade and trafficking and, therefore, many sites where payments are required<sup>7</sup>. In 2001, buyers from the United States paid upwards US\$200,000 to travel to Israel for organ transplants. Organ sellers, however, receive relatively little for their contribution. Scheper-Hughes (2003) found that sellers who’s organs were removed in Israel received anywhere between US\$3000-15,000, depending on their country of origin (Scheper-Hughes, 2003). Cohen (1999) found that in the mid-1990’s, female organ sellers in India received as little as US\$1200 per kidney, which was in many cases far less than was promised by a local broker. Many who sell a kidney do so to pay off debts and to rise out of poverty; however, few ever do (Cohen, 1999; Goyal, Mehta, Schneiderman & Sehgal, 2002). Overall, Scheper-Hughes and others urge readers to reconsider their notions of right and wrong when it comes to viewing the body of the other as a repository of “spare parts.” Through her work, Scheper-Hughes connects the disturbing reality of trafficking and trade to the relations of global

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<sup>7</sup> Scheper-Hughes (2003) notes that not only is poverty a driving factor in selling an organ, but also tends to be the reason others become involved in brokering or supporting organ trade and trafficking.

capitalism, and especially the relations of the north to the south, the west to the east and the first to the third world.

Scheper-Hughes also tackles many of the more philosophical and cultural components of conceptualizing the body in the trade in human organs. In the compilation *Commodifying Bodies* (Scheper-Hughes & Wacquant, 2006), she and colleagues from anthropology, sociology, medicine, law and ethics discuss how the body has been removed from the self and how it has been reconceptualized as a separate, divisible object, commensurable and commodified, in a number of different ways. For example, Tober (2006) discusses the marketization of reproductive goods such as semen. Cohen (1999) calls this reconceptualization the new 'ethics of parts' where the body, as a divisible, commensurable object, is acted upon and through rational economic decisions in response to market demands. This breaking down of the body as separate from the self without all of its personal and traditional meanings is arguably not new. The medicalization of the body has solidified this way of looking at our own and others' bodies, particularly when it comes to defining disease as being of the body, as opposed to being of the person, environment or society (Sharp, 2006). However, what is new is that individuals have turned this way of thinking upon themselves, that is, they come to see themselves as a vessel containing parts with dollar signs attached. For example, in rural Eastern Europe, men and women looking for work and suffering from deplorably low incomes sell either a kidney or their bodies for sex in Istanbul. And while they face a lifetime of social ostracism from their communities, the prospect of money is difficult to ignore, and so the body is commodified (Scheper-Hughes, 2003). Thus, despite the social and cultural knowledges that exist about the body, the commensurable body is perhaps

the most pervasive conceptualization today, particularly for those desperate to improve their economic situation.

Considering this brief overview, there is a need to work through some of the basic assumptions of Scheper-Hughes' work in order to identify exactly how the role of the buyer in organs markets is realized. The remainder of this section highlights the assumptions that underlie Scheper-Hughes' critique of the values and norms that create organ buyers and sellers around the world. These assumptions are drawn from a predominantly political-economic description of the utility of the bodies of global others. Thus, the following is a review of important theoretical developments useful for conceptualizing the political economy of the global, medical body<sup>8</sup> and provides a basis to help us understand how Canadians might easily see the body of the other as a vessel of "spare parts."

When thought through logically, participation in organs markets might simply be seen as a matter of logistics; the planning and carrying out of an activity to achieve a desirable outcome, a new kidney. But the situation is arguably more complex. Assuming that we are in an era of intense globalization and late capitalism, the movement of bodies all over the world is easier than ever before. Taking a step back, however, we find some fundamental questions that require answers. First, how have we come to this point? How have we, as the human race, come to a point where putting one life at risk to save another, based on a monetary exchange, is seen as acceptable? And how can we have come to imagine our own body parts as objects to be exchanged for cash? What can this mean for bodily integrity and perceptions of self and others when humans sell their body parts?

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<sup>8</sup> Please note that much of the following section has been published elsewhere (Peters, 2010).

And finally, what role has the globalization of interactions, communications and ideologies played in the proliferation of markets in human organs?

First, an important consideration for investigating organ transplantation, procurement and trade is the pervasiveness of understandings of the *body as object* in post-industrialized societies. For example, medical knowledge and terminology promote the idea that “the body” is ill and not the person (Sharp, 2006). Such language has the effect of objectifying the body, making it an alienable part of the individual. Assuming the body to be an alienable part of the individual has other important consequences for how we relate to bodies. Wilkinson (2003) discusses the ethical dilemma of treating the body as an object and the danger of immoral “exploitation” or using others for personal gain. Using Kant’s principles, Wilkinson argues that we must never treat people as means to an end (use value) but only as ends-in-themselves (use and intrinsic value), because “when we become focused on a person’s...usefulness to us, we have a tendency to disregard the fact that she is an autonomous being who deserves respect” (p. 37). From an ethical perspective, processes of organ transplantation and trade, and the institutions that support them, tend to treat people as objects only based on their instrumental or use value of prolonging life.

Given that people are treated as objects only, bodies are similarly objectified in a new “relation of production.” In his work on organ sale and trafficking, Pálsson (2009) applies Marx’s notion of relations of production to the body. He argues that the mechanization of factory work that led people to become merely living appendages of machines is mirrored in a new form of “human mastery” that extends “to the bodies of the workers themselves” (p. 297). Here, one’s *productive value* becomes the ability to extract

organs, and *human labour power* becomes one's ability to sell organs in exchange for cash. Thus organs, like labour, are "alienable objects" for sale. Pálsson states that "estrangements represented by the biotech mode of production – the fragmenting, trafficking, and hybridity of body parts...mirror, up to a point, the objectification and alienation of 'species-life'..." (p. 302). Arguably, in the current context of late capitalism, the body is yet another site of production and Marxist conceptions of objectification and alienation of workers and labour can be applied to bodies and organs in the new "biotech" mode of production. In terms of the international trade of organs, there is an exploitation of the productive value of bodies of the underclass, while there is valuing of life for those with the money to buy the organs they require. Thus, body parts are alienated and estranged from the individual and perceived as objects for donation or sale.

The objectification of the body within both the medical realm and the "biotech" mode of production has served to change our understandings of what the body is and means, and how it can be altered. Objectification has spurred a strong interest in and dependency on *biotechnology*. Following the release of the *Human Genome Project* in 1990, Paul Rabinow (1996) claimed that we are now living in a biosocial world where the body as object is an increasingly malleable thing. For example, the project made possible the creation of designer babies with all the best, socially defined, physical traits. Similarly, Pálsson (2009) states that, "humans now reinvent themselves in a new sense and on a fundamentally new scale, deliberately altering their bodily constitution and development by exchanging genes, tissues, and organs..." (p. 291). What is more, the impact that this reinvention-ability has had on individual identities is astounding; anyone can log on to the internet, pay a fee and learn about their genetic makeup, predispositions

to illness and ancestry. This new information effectively creates new ways of knowing the self, new identities that would not have existed in previous times (Pálsson, 2009).

Ultimately, advances in genetic research and biotechnology generally are changing perceptions of what is available for knowing and, perhaps more importantly, for consuming. In today's biosocial world, social lives and identities are tied to biology through technology, which serves to change individual understandings of the body and perceptions of what is technologically and medically possible.

Particularly in the case of human organs, advances in medicine and the widespread use of cyclosporine in the last few decades has led to an increase in transplant surgeries, and higher confidence in health outcomes of both donors and recipients (Fox & Swazey, 1992). Arguably, knowing that the technology to procure an organ and survive transplantation exists has a significant impact on increasing individual desire (and desperation) for treatment. One's identity becomes intimately tied to realizing a healthier life, which is a primary goal regardless of the cost (financial or human). For someone waiting for an organ today, knowing that there is a relatively easy and safe cure for their illness, but that it is unattainable due to a lack of donated organs, presumably causes a great deal of frustration.

It seems logical that a discussion of "body as object" necessarily involves a discussion of *body as commodity* as in many cases these concepts have the same meaning. In terms of understanding why someone might make the choice to purchase organs rather than wait for them through a donation system, it becomes even more important to consider how organs became commodities in the first place. Social scientists have developed a number of theories to explain the process through which objects become

commodities; how meanings change over time and how things once considered “sacred” are given a cash value. Arguably, since they are tied to life itself, organs at one point fell within the latter “sacred” category, but organs are clearly now objects for sale.

Using *exchange theory*, Marx (in Morrison, 1995) explained that commodities have both a use value and an exchange value and are primarily social objects because these values rely on judgments, and because they circulate within social systems in response to desires and demand. Appadurai (1986) argues that because of the social nature of commodities, we can map the “human transactions that enliven them” (p. 2). If we consider commodities as 1) socially defined and 2) always “in motion” in their trajectory, we can see how all things can be said to move into the “commodity territory.”

Building on exchange theory and taking an anthropological approach, Igor Kopytoff (in Appadurai, 1986) discusses the concept of the *cultural biography* of objects and how they move in and out of exchange, or the “commodity territory.” He explained that “commoditization is best looked at as a process of becoming rather than as an all-or-nothing state of being” (p. 73) and why something “becomes commodity” depends on context. For example, the slave is captured and is stripped of his previous identity. As a nonperson, he becomes a commodity to be purchased for his labour, but as he is integrated into a new society, he is reindividualized, decommodified. However, at the moment he is traded among slave owners, he is recommodified. Thus, some objects, especially humans, become commodities only in specific social contexts. Thus, objects on their trajectory can be said to be commodified, decommodified or recommodified depending on the situation.

Building on Kopytoff's model of *cultural biographies*, Appadurai (1986) argues that assuming different cultures create different "social contexts," it is necessary to consider why some objects become commodities no matter the culture. Cultural frameworks are the moral, symbolic and classificatory standards of a particular time and place that determine whether something is exchangeable (Appadurai, 1986). Since people do not share one cultural framework, the "degree of value coherence may be highly variable from situation to situation," (p. 14) and, thus, cultural frameworks break down. In cases of *exchange across cultural boundaries*, all that can be "agreed upon is price..." (p. 14). Contexts can exist, or can be created, in light of disparate cultural values. For some commodities, like bodies, it is these contexts that allow body parts as objects to enter into the commodity territory. In the case of human organs, they have entered the "commodity territory" because of the current shortage in most affluent nations. Presumably, organs will remain in the commodity territory so long as there is a demand for them that is not met with an increase in available donated organs. Scheper-Hughes (2003) states:

What goes by the wayside in these new medical transactions is longstanding modernist and humanist conceptions of bodily holism, integrity and human dignity, let alone cultural and religious beliefs in the 'sacredness' of the body. (p. 204)

Thus, where organs were perhaps once considered "sacred" and non-commodifiable, they have become commodities where the cultural frameworks protecting them have broken down.

Social scientists have also made the connection between globalization and the intensification of the organs trade. Broadly speaking, processes of *globalization* over the last 30 years have included the breaking down of the modern welfare state through market liberalization (McKeen & Porter, 2003), the expansion of transportation and communication (Steger, 2009), and the all-important hunt for ever cheaper production costs. Globalization has been described as the “internationalization of capitalism” (Seidman, 2009, p. 19) and there exists a global socio-political class system that furthers the success of those who already hold the power (Wallerstein in Seidman, 2009). Scheper-Hughes (2000) states that even organs tend to flow through “the modern routes of capital: from South to North, from Third to First World, from poor to rich, from black or brown to white, and from female to male” (p. 193). Similarly, Sharp (2000) argues that the transmission of exchange value onto the “socially expendable people” (p. 296) of the world has been a common thread throughout history, such as slavery. Sharp also elucidates humanity’s seemingly historical compulsion to further commodify similarly expendable parts, noting the more contemporary practices of international surrogacy. Processes of globalization over the past few decades have dramatically changed the way people are connected to their social world, and especially the way we understand the production and exchange of goods, such as organs.

It is also important to note the impact of globalization on the breaking down of cultural frameworks. Steger (2009) explains:

As images and ideas can be more easily and rapidly transmitted from one place to another, they profoundly impact the way people experience their everyday lives

[and] culture no longer remains tied to fixed localities...but acquires new meanings that reflect dominant themes emerging in a global context. (p. 40)

Arguably, the global context erodes local cultural frameworks. For example, in the past, national welfare systems, such as in Canada, tended toward valuing the donation of organs and altruism over commodification (Schweda & Schiktanz, 2009). While this is still reflected in the provincial donation systems, liberalization and the spread of consumer culture have enabled desperate people to travel elsewhere for their organs. At least to some degree, previously held values such as altruism in organ procurement are breaking down.

Theorists have also discussed the impact of globalization on the organ trade in reference to medical tourism. Medical tourism involves individuals travelling to foreign countries to procure medical treatments when the same treatments are not available (e.g. are not covered by insurance, cannot be paid for, are not approved treatment methods, etc.) in their own country<sup>9</sup>. Scheper-Hughes (2002) describes a case in Israel where a covert transplant company operates between Turkey, Russia, Moldavia, Estonia, Georgia, Romania and the United States. Over the course of five days, buyers and sellers are brought together for surgery, followed by recovery, and are then flown home. The organ “package” costs upwards of US\$200,000 in 2001 with some of the money going towards bribing transportation officials, and renting hospital and hotel rooms (p. 72). Arguably, without economic dominance and the spread of consumer culture, medical tourism might not even have been possible. In another example of the effects of globalization in relation to the organs trade, Scheper-Hughes (2002) points to the disturbing reality of the impoverished living in developing or periphery nations. In Chennai Slum in South India,

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<sup>9</sup> See for example [www.allmedicaltourism.com](http://www.allmedicaltourism.com).

a local doctor distributes “right to sell” propaganda to entice severely impoverished individuals to consider selling a kidney. Unfortunately, money earned from selling a kidney only lasts so long, and debts brought on by lack of work or corrupt housing establishments and fines quickly add up once again. Indeed, the situation is as Scheper-Hughes states:

Globalization has encouraged the development of a new form of ‘debt peonage’ in which the commodified and fetishized kidney occupies a critical role as collateral. Today, the spare kidney represents everyman’s last economic resort, one’s ultimate collateral. (p. 70)

Globalization, as an economic and cultural process, can have devastating effects as the spread of consumer culture leads to the intensification of the trade in human organs, especially in developing countries.

Cohen (2002) further illustrates the connection between globalization and the organs trade through his discussion of *biopolitics* and the recognition of the local and international other. Cohen explains that, historically, India has had a commercialized blood procurement system and brokering remains a major “social and economic form”. When transplant medicine was improved in India with the release of cyclosporine, clinics only had to show that they had some form of recruitment and treatment plan to carry out transplants as they wished. Without an overly regulated system, markets flourished with those able to pay for treatment receiving the kidneys of the poor. More recent attempts to stifle the trade, Cohen says, have led to the simultaneous outlawing of organ trade through formal policy statements and allowing organ brokering to continue, such as allowing clinics and brokers to advertise in poor areas. This is done in order to restrict

foreign consumption, but not domestic consumption<sup>10</sup>. The trade is allowed to continue within the country as it lacks a state sponsored organ supply system of any kind. Importantly, Cohen develops an analysis of kidney trade as tied to the biopolitics of late capitalism. He argues that new medicines in India coupled with a conservative use of familial organs (organs donated by a family member) allowed for the identification of potential donors from within poor populations. Medical knowledge and demand led to a recognition of poor, mainly female, bodies as sights for organ production, but at the same time relied on suppression of sameness beyond the body context. Poor populations, he explains, were made “same enough” in medical discourse and practice to allow them to become organ suppliers (p. 12), but not so “same” as to alert the conscience of a wealthy buyer. That is, a poor man who sells a kidney as a last resort is merely a sacrifice being made by an inhuman, dirty, poor and worthless other and not a sacrifice by someone with any real value. Cohen likens this case to Agamben’s (1998) *bios*, a state of political, social and economic recognition, and *zoe*, a state of bare-life and “exception” that is determined by sovereign power in a state of self or state preservation, and where death is not murder. In the state of exception, the selling of one’s kidney cannot be considered a true sacrifice. Arguably, the recognition and the biopolitical suppression of the other play

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<sup>10</sup> Interestingly, the unrestricted domestic consumption of organs that is found in India counters the arguments presented by Scheper-Hughes and others that organ trade is an issue of global class dominance only. To find that class dominance within India maintains the trade is to find that the typical notion of trade as between white, western and affluent buyers and brown or black, eastern and poor sellers is not entirely accurate. Indeed, the use of impoverished bodies for organs harvesting occurs within as well as between nations. This oversight in the literature may demonstrate a shortcoming of the common ways in which social scientists come to understand and criticize organs trade.

an important role in creating opportunities for organs trade both in and outside India.

Cohen states:

The line between self and other is no longer the problem of the nation. People unlike oneself – not kin, not cared for, far away in structural or spatial terms – are disaggregated and their parts incorporated by suppressing recognition of difference. [...] With both equivalence and difference suppressed, flesh is effectively mobilized. (p. 23)

Such observations may be particularly true in cases where the desperation to “preserve” a privileged class necessitates a state of exception where the worth of an organ supplier cannot be called into question. Similarly, Scheper-Hughes (2002) supports Cohen’s ideas in her discussion of commodity fetishism in organ trafficking where she explains the fetishized kidney is in fact a fetish of life, the result of a *make live* and *let die* circumstance that only benefits the already secure and privileged class.

To summarize important considerations elucidated here, among social scientists, the commodification of the body and the fragmentation of its parts in market-based systems of exchange present a troubling development in human desires and understandings of bodily integrity. This critical literature on the role of wealthy, mainly white westerners in organs trade, paints a bleak picture indeed. Based on this analysis, we find that the affluent have come to rely on the most impoverished and marginalized who supply body products in unfair exchanges, often resulting in the bolstering of corrupt middle-men who use the poor as a way of turning a profit. Relationships between people become economic to the fullest extent, where self-preservation is tied to consumption practices that are organized through markets, where the body of the other is treated as any

other commensurable object. As such, Canadians, as well as Americans, Western Europeans and elites in the underdeveloped and developing world can be understood as inherently criminal in that they participate in the illegal buying and selling of human organs by virtue of their lack of respect for human dignity and equality. Therefore, based on this discussion of how body parts become objects for sale and the new ways in which we use the body of others, Canadians are cast as selfish, market oriented, consumption minded and ultimately focused on consuming ever more intimate areas of human life.

Given that Canada is a capitalist country that operates on the basis of neo-liberal ideologies, it is not difficult to imagine that values that underlie practices that treat bodies as objects and commodities are indeed prevalent; mainly individualism, privatization and economic exchange (Coburn, 2006). Arguably, if it were the case that Canadians are so “consumeristic,” it may be reflected in not only how we treat one another on an everyday basis, but also in our participation in the organs trade. In terms of our treatment of one another, it is important to note that the sale of sexual services is not illegal in Canada (Turschic, 2010), and it was as recent as 2004 that a legislated ban was placed on the payment of surrogate mothers beyond compensation for costs incurred (CBC, 2007). In terms of organs market participation, there have been a few notable cases. For example, in a 2005 article in *Foreign Policy* magazine, Scheper-Hughes includes Canada among the “common countries of origin for those buying kidneys” (p. 26). Similarly, a 2006 news article published in the *National Post* discussed an investigation into Canadians who travelled to China to receive organs harvested from non-consenting prisoners (Blackwell, 2006). Clearly, Canadians are buying organs abroad. Coburn (2006) states, as citizens of a capitalist country “we are, according to neo-liberalism, our own products; what happens

to us is entirely due to our own efforts and the greatest good is that which frees individuals from any constraints” (p. 62-63). Perhaps when it comes to obtaining organs when they are in short supply, it may be the case that we have a tendency to find the best option for freeing ourselves from our burden, which in the case of waiting for a kidney would be the international trade in organs. Overall, we can see how Canada might very well constitute the kind of society that would see the buying of organs from others as merely an extension of already engrained capitalist ideologies, where commodities are available to those who have the money to afford them.

Bodies and body parts are commodities and it may be assumed that the conditions that create organ buyers are present in Canada. People waiting for donated organs who are relatively affluent (relative to others in the world and within Canada) become “potential” buyers by virtue of their ability and supposed desire to participate. However, the accuracy of this claim, this labeling of the “Canadian organ buyer,” is tenuous and ought to be examined. One shortcoming of this conceptualization of the Canadian organ buyers is that it lacks acknowledgement of Canada’s ethnic and cultural diversity. Scheper-Hughes essentializes northern-western societies by assuming that we are all “white, western and affluent.” In fact, we are not all “white” any longer. According to Statistics Canada, as of 2006, there were just over 2.5 million immigrants living in Canada whose country of origin was located in Asia and the Middle East, regions where organs trade and trafficking are known to be the most prevalent. There is evidence to suggest that foreign national and immigrant status are predictors of participation in organs trade, an issue that will be discussed in later chapters. By assuming that North Americans, in particular, are organ buyers by virtue of their relative affluence and desire, theories that seek to explain

and criticize organ trade fail to accurately represent the population under consideration, and are thus weakened.

One might also consider how the role of organ buyer takes shape, particularly given the current organ transfer system in operation in Canada. There are significant ethical and moral considerations involved in making the decision to travel abroad or stay in Canada to wait for a donated organ, and it is likely that the values underlying such choices are in opposition to one another. On the one hand, travelling abroad involves the valuing of self-preservation over others and the valuing of money over fairness and equality. On the other hand, waiting for a donation involves the valuing of voluntarism, altruism and the caring nature of the giver who is doing so under no threat or coercive force. This, of course, may only be true if the choice to stay is not simply due to one's inability to afford to travel abroad. In order to see how these opposing values play out, we can look to our current system of organ transfer as the institutional context in which patients make decisions, and we can consider the influence that institutions have on patients who are in a position to participate in organs trade. That is, we can seek to better identify the true motivations underlying decision making, and determine where Canadians fit on the conceptual polarization of "consumers" versus "altruists."

The next section discusses the role of values underlying service provisioning in blood and organ transfer, referring to the work of Richard Titmuss. It is important to note that Titmuss discusses the dangers of regulated markets for human products (i.e. government systems that coordinate the purchase of human products from individual private "sellers"), and not necessarily the dangers of international organ markets. Still, through his analysis, it becomes clear that the values underlying "market-based" systems

of blood donation are similar if not the same as those underlying the international market for human organs, such that they are similarly exploitative of individuals who fall prey to the coercive force of economic insecurity.

Following this discussion on Titmuss, the subsequent section highlights the complex social and political nature of Canada's health care and organ transfer system, particularly noting Canada's commitment to a voluntary opt-in donation strategy. This discussion will demonstrate that despite the tendency for Canadians to, at times, exhibit qualities of a "consumption minded organ buyer," such capitalist intensions are not reflected in the country's service provisioning, such that Canada does not have a market-based organ transfer system. And, in fact, its system, in many ways, works to counter patients' desire to travel abroad for the purpose of buying organs. Interestingly, an analysis of the Canadian case shows that while the extremes with which authors such as Scheper-Hughes discuss the dominant moral trends in the western world towards organs trade are present, Canada is a neo-liberal economy that ultimately must treat all medical services, including transplants and organs, as commodities to some extent. What impact this has on the decisions of the users of such a system is, at this point, still unknown. Thus, the next section looks in-depth at the complex nature of care provision in Canada and where Canadians fit, in terms of dominant values, on the scale that places consumerism on one end and altruism on the other.

### ***Welfare State Medicine and the Case for Altruism***

*"...blood as a living tissue may now constitute in Western societies one of the ultimate tests of where the 'social' begins and the 'economic' ends. If blood is considered in*

*theory, in law, and is treated in practice as a trading commodity then ultimately human hearts, kidneys, eyes, and other organs of the body may also come to be treated as commodities to be bought and sold in the marketplace.” (Titmuss, 1970, p. 158)*

Published in 1970, one book forever changed our understandings of the role of altruistic “gift giving” in contemporary systems of blood and organ transfer and its connection to politics, welfare and morality in the developed world. That same book would also lead to a complete overhaul of the entire United States blood donation system as it identified some striking and potentially dangerous differences between it and the British National System. Titmuss’ *The Gift Relationship* (1970) provides an extraordinary look into the social, economic, political, ethical and moral justifications for avoiding at all costs the commodification of organs, tissues and blood, and for supporting a freely voluntary, unpaid donation system in these human goods. Titmuss explains that due to the nature of modern society and the constant advancement of technology, increasingly more people must step forward to give of themselves in order to avoid shortages and maintain adequate treatment programs. He argued that institutions and policies must provide people with opportunities to be altruistic so that it is not only those who are in need of money that contribute to the pool of available blood and tissues, and potentially contaminate it. Ultimately, by mapping the motivations that drive donation, and through a review of various institutions’ policies and programs, Titmuss found that the U.S. system constituted a social failure as it was putting lives in danger. He concluded that gift giving and the simultaneous discouragement of alienation, which is prevalent in relations under

capitalism, are, therefore, fundamental for the successful maintenance of modern societies.

Titmuss begins by speaking of blood as the life force that links all humans in vital, cultural, spiritual and moral ways. How we treat blood, that is, how we organize ourselves around the collection and distribution of blood and blood products, he argues, speaks to the human values that prevail in a society. He discusses the demand and supply of blood historically in England, Wales and the United States and urges the reader to consider blood systems as being organized around not only demand, but also supply. Furthermore, he argues that since demand inevitably depends upon supply, the focus of researchers and policy makers ought to be on the supply of such human products. He mentions that if this is done properly, crisis demand and response in human goods can be avoided as it can lead to questionable practices and methods for collection and allocation. Titmuss also usefully identifies the historical moment where the demand for blood became a global phenomenon; when it was agreed that blood was a “vital preventive and therapeutic agent” (p. 33), which helped to create a modern “endless life”. He claims that with improvements in technology, the demand and supply of blood in the world grew in response to the proliferation of ever more incredible feats of surgical achievement. Consequently, there has been a great deal of variety in how nations go about procuring and allocating such needed resources, of which organs are now a part. To demonstrate this variety and to identify inefficiencies and challenges, his work compares the British donation system and the United States market-based system of paid donation.

Titmuss draws on the work of Mauss and Levi-Strauss to define the common theme of “gift giving” in blood and tissue donation (as altruism and gifting are contained

within the word “donation”) and its role in maintaining systems of procurement and allocation. He presents, for the first time, a *typology of donors* that allows him to identify the motivations behind giving of the self and the role of institutions and policy in confirming and allowing for those motivations. Eight donor types are presented, and for each Titmuss seeks to determine the level of spontaneity and altruism involved as motivators, and notes that all types are “molded by cultural and moral values” (p. 89). The first five types relate almost directly to the U.S. systems of the past and some of the present, with the remaining three types relating to the British (and Canadian) systems. All donor types are presented alongside a discussion of the systems that support such donors, while potential dangers associated with the products provided are discussed more fully for some than for others: 1) *the paid donor* does not see their contribution as a gift, rather their “giving” is based on market prices and demand, a privatized venture that is supported by privatized systems where mislabeling and illegal tampering lead to poor quality products and lack of exclusion of “drug addicts, alcoholics, and carriers of hepatitis, Malaria and other diseases” (p. 76); 2) *the professional donor*, who donates on a regular basis and receives a salary for doing so, undergoes screening and regular appointments in a private system; 3) *the pay-induced volunteer*, who is not motivated by money but donates nonetheless, is common in areas where organizations compete for donors (i.e. where there are multiple collection facilities), for example, members of workers’ unions who see the money as compensation for their time rather than for their blood; 4) *the “responsibility fee” donor*, who has received blood in a hospital and who must now donate in order to repay their debt to the hospital’s blood supply (enforcing a moral obligation), though, the ‘replacement charge’ is higher than needed by the hospital

and there is often a great deal of waste; 5) *the family credit donor*, who donates to hospitals or other collection facilities as an insurance for future need to be used by the family; however, replacement charges are often higher than the portions used or required by the facility; 6) *the captive voluntary donor* includes prisoners and military personnel, which presents ethically complicated cases due to differentials of power, authority and subordination, thus making it difficult to determine whether products are given spontaneously or altruistically; 7) *the fringe benefit voluntary donor*, who receives tangible reward for donation, such as ‘Thank You’ medals, free meals, days off work, vitamin supplements, etc.<sup>11</sup>; and 8) *the voluntary community donor*, who acts on free will under no circumstance of power, constraint, coercion, shame or guilt and with no guarantee of reward or return. It is through this typology that Titmuss begins to identify a range of motivating influences that may lead individuals to either sell or donate body products.

Assuming that these types present a scale leading from the least spontaneous and altruistic to the most, Titmuss goes on to identify the social characteristics of blood donors who fall within this range. In his analysis of the American system, he finds that, from 1965-67, 52 percent of all donors were contractually tied to replacement programs, five percent were captive and only nine percent were voluntary community donors; however, the latter form of donor was believed to be the norm. Most strikingly, he found that donors were typically unskilled, unemployed, mostly black men, between the ages of 16 and 60 who received between US\$5-\$50 per unit, while recipients typically comprised

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<sup>11</sup> Fringe benefits were not only common during Titmuss’ time, and he mentions this activity was common in the U.S. and the U.S.S.R. (now Russia), but they are also common today. Currently, Canadian Blood Services provides free snacks at the time of donation and runs a donor recognition program which celebrates milestone, such as the 10<sup>th</sup>, 25<sup>th</sup>, 50<sup>th</sup>, etc., donations. Donors are awarded pins, cards, certificates and others small tokens.

the middle and upper classes, and tended to be white. He concludes that the “redistribution in terms of ‘the gift of blood and blood products’ from the poor to the rich appears to be one of the dominant effects of the American blood banking systems” (p. 119). These results of the American system are then sharply contrasted with those of England and Wales where the dominant donor type was voluntary community donors (as is supported by the national system). Donors included many more of the middle and upper classes, many more women, and a fairly even distribution of age groups. Thus, donors comprised a far more representative sample of the population than in the American system. He also found that there was more blood available in the systems of England and Wales than in the American system, which is a major indication of how well the system is providing needed blood products. Titmuss argues, then, that these systems reflect very different social and moral values, and he concludes that in societies where donors are paid to give blood, the poor become the sites of blood production, and such systems are less successful in providing a sufficient supply.

Titmuss also highlights the dangers of market-based models and incentivized donation systems as a result of heightened risk, particularly for recipients. He explains that when in desperate need for money paid donors are reluctant to provide their full medical history, to discuss recent activities that would present a likely infection or disease, or to reveal drug use and other dangerous habits. As a result, there is a high risk to the recipient given that blood cannot be fully tested for all possible contaminants, hepatitis being the major concern. Further, Titmuss explains that due to the probability of entire caches of blood having to be destroyed due to infectious disease, shortages will increase over the long term, thereby intensifying the risk to recipients who rely on the

truthfulness of donors and the proper handling and labeling of blood products in private facilities. Said simply, the sick bear the costs of systems that run high risks of spreading infection and that perform in the interest of profit. However, Titmuss acknowledges that those who support fee-based 'donation' wish to make "an economic case against a monopoly of altruism" that is seen as less reliable than economic incentive. But he warns, "it is easier for societies to abandon altruism as a motive for giving blood than it is to abandon the principles of economic man once they have been institutionalized and accepted" (p. 187). Ultimately, he argues that the market will fail in providing efficiency, reasonable costs and, most importantly, a safe blood supply.

Finally, Titmuss presents one of the most compelling arguments for altruism in the giving of human blood and tissues, that is, he presents the concept of the *universal stranger*. The argument for why this concept is so important can be stated as follows: because giving blood into an anonymous system, i.e. to an unknown other, does not allow for the reciprocation of the gift on the part of the recipient, such that there can be no expectation or guarantee to the donor of a reward, institutions must make the gift seem socially valuable. What is more, this notion of the *social value* of free voluntary donation is a necessary component of modern societies, which require people to step forward to give of themselves, so that somewhere down the line, their generosity is repaid in a meaningful, socially responsible way. He argues, then, that social policies for organizing the procurement and allocation of human products must take into account both quantifiable aspects of man as well as the "unquantifiable and unmethodical" (p. 224). Further, Titmuss states, "processes, transactions and institutions which promote an individual's sense of identity, participation and community and allow him more freedom

of choice for the expression of altruism and which, simultaneously, discourage a sense of individual alienation” (p. 224). He thus concludes that anonymous gift giving is important for the continued functioning of modern societies, particularly as more and more people are needed to step forward to help advance technologies, and so long as people are provided with opportunities to be altruistic, they will be. Therefore, nations that promote social policies and the concept of altruistic, anonymous gift giving in the procurement and allocation of human products will be more successful in their attempts to provide a safe and adequate supply over the long term.

Though things have changed since Titmuss’ time, his contributions speak to some important considerations for the work undertaken in this study. Ultimately, what can be taken away from Titmuss is that systems that coordinate the procurement and allocation of human products are built upon strong social, ethical and moral values that permeate the public service landscape. Arguably, how a service is organized reflects not only the values of the public more broadly, but also the limitations as to what individuals and groups within a particular society are willing to allow. Of course, it is debatable whether individuals have adequate knowledge of service provision that would allow them to set reasonable limits and hold officials accountable should they fall outside of the common sentiment. Still, it can be generally understood that within democratic states, health care and its organization are based upon a shared consciousness promoting particular ontological principles, understandings of what is real and can be said to exist (e.g. the “sick” body, the dehumanized organ, etc.) and epistemological principles, understandings of what is knowable and how knowledge is to be rightly obtained (e.g. transplant practice and procedures). There are likely, then, a certain number of services

that people demand and expect to receive as members of that shared consciousness. For Titmuss, a safe supply of blood and blood products that are given freely without coercive force is one of them.

By expanding Titmuss' work on blood systems into discussions of organ transfer systems, we see that he presents compelling arguments for the continuation of altruistic voluntary organ donation, or opt-in strategies. Specifically, he would find danger in procuring organs from people who need money as they may not be in peak physical condition; however, this could be mitigated through appropriate screening strategies, which will be discussed later. Still, he would challenge the ideology of paid donation systems and would likely see such a system as evidence that a nation has begun sliding down a slippery path that slopes away from social responsibility and towards the commercialization of everything, including bodies.

Importantly, Titmuss illustrated how different types of institutional arrangements support particular motivations behind giving of the self. Canada has a voluntary organ donation system, but continues to struggle to meet the demand for organ transplants, and especially for kidneys. By considering the case of Canada, it is possible to determine whether Titmuss' basic assumptions about values and their influence on the provisioning of health care services are accurate. The next section, therefore, discusses why Canada is experiencing shortages and the actions that have been taken to address them, as well as the continued participation of Canadians in the international organs trade. What becomes clear is that Canada has an altruistic, voluntary opt-in donation system because, from the perspective of the public, organs are not commensurable, they are not commodifiable and, therefore, transplants should be procured from individuals who are willingly giving of

themselves. However, the organization of medical services requires the exchange of funds to support organ transplant services; as well, private service providers operate within their own interests. In this way, organs are commensurable; they represent very real costs that must be balanced by private service agents. So, perhaps in spite of dominant ideologies espoused by organ procurement organizations about the importance of gift giving, Canadians understand that anything can ultimately be obtained for a price. Perhaps knowing that anything is obtainable with a certain amount of money, and when faced with a requirement that cannot be fulfilled, individual need overrides a strong commitment to particular social values. It is not surprising, then, to find that patients in desperate situations, who have the money to purchase organs, choose to do so through whatever means necessary. It should be noted that the buying and selling of organs would of course not happen overtly in Canada's organ transfer system; however, it is difficult to prove that some form of exchange among family members or friends does not occur in the instance of live donation.

Using transfer systems as a means to identify dominant ideologies within a society, as Titmuss claims, will not necessarily yield the most accurate description of what values are held in highest esteem. For example, based on the available sources, it appears that despite Canada's reliance on voluntary donors, challenges exist, particularly at the level of administration, and there remains some confusion around the commensurability of organs. Therefore, there is an opportunity to find alternative ways to uncover the dominant social values that both impact and are impacted by organ transfer systems, an opportunity that this study takes up.

***Canada: Organ Transfer through “Opt-In” Donation***

As mentioned earlier, there is a general expectation that medical services are designed to improve the quality and quantity of life of individuals experiencing ill health. An individual’s ability to live free from pain and to take part in normal social activities is considered a right. As such, Canadians demand particular services with particular outcomes. Organ transplant is one of those services. Considering more specifically the case of individuals with renal failure, the organization of health promotion campaigns and the provisioning of diagnostic testing, dialysis treatments and transplant are included in the standard “care package” (see London Health Sciences “Patient Handbook” for its kidney transplant program). From a policy perspective, each of these steps relies on a careful balancing of funds, whereby it is hoped that spending on health promotion will reduce the strain on the health care system that treatments and transplant create (Inman, van Bakergem, La Rosa & Garr, 2011). A 2008 news release from the Ministry of Health and Long Term Care estimated that “treatment for diabetes and related conditions such as heart disease, stroke, and kidney disease currently cost Ontario over \$5 billion each year.” In the same news release, the province committed CAD\$741 million over four years towards a “Diabetes Strategy,” a health promotion initiative aimed at improving access to services and technology, and reducing the incidence of disease and, thus, subsequent strains on the health care system. A commitment of \$741 million towards health promotion is arguably small given the estimated costs of treatment set at \$5 billion annually. In terms of the cost of treating patients experiencing end stage renal failure (ESRD), according to the Canadian Institute for Health Information (CIHI), the average annual cost of keeping one person on hemodialysis in the clinic is approximately

CAD\$60,000. Alternatively, the one-time cost of kidney transplant is roughly CAD\$23,000, with an additional CAD\$6000 to cover the costs of follow-up care and medications, a difference of over \$30,000 per patient. Thus, a simple subtraction shows that the savings from transplant are indeed striking. In fact, it was estimated that “in 2009, more than 15,000 patients living with kidney transplants saved the health care system an estimated \$800 million” (CIHI, 2011). Considering that the typical wait for donated kidneys in Ontario is anywhere between four to eight years<sup>12</sup>, one patient who waits for six years (a safe median) and receives dialysis treatments in the hospital costs the system approximately CAD\$360,000<sup>13</sup>. Given the high cost of treatment, there is arguably significant justification in performing more transplants in order to get people off of dialysis. One way that the government is trying to reduce the cost burden of keeping patients on dialysis in the hospital is through home dialysis. Dialyzing in the home will be discussed in more detail later, but it is important to point out that the costs to the system are significantly reduced due to the fact that nurses are not needed, and the overhead for maintaining the dialysis clinic are avoided (McFarlane, 2004). Still, it is clear that from both the perspective of patients as well as the medical system, a transplant is the end goal as it provides a least cost option.

Of course, meeting the needs of people with end stage organ failure requires an organized organ transfer system. In Canada, the form and operating procedures of organ transfer systems vary depending on the province or territory; however, all systems must operate on a voluntary, altruistic donation basis. As mentioned, this system is also

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<sup>12</sup> This information was developed by combining wait time estimates given by all of the respondents.

<sup>13</sup> It is also important to consider the costs associated with patients who are ineligible for transplant and who remain on dialysis indefinitely.

referred to as an opt-in strategy whereby donors must register their willingness to donate upon death, or “opt into” donation. For example, in Ontario, the Trillium Gift of Life Network is the provincial organ procurement organization (OPO) that oversees the registration of donors. Trillium is mainly responsible for the training and employment of regional donor coordinators, building public awareness and education, building awareness and support for organ donation within the medical system, dispelling myths, and maintaining provincial statistics (Trillium Gift of Life, 2011). In addition to the role of the regional OPOs like Trillium, individual hospitals contain organized and regulated transplant coordination teams who oversee all aspects of the organ transfer process to recipients, with the goal of reducing all possible harm and retaining anonymity in the system. Though each system may reflect small differences in the administration of procurement and allocation, each provincial OPO operates relatively independently<sup>14</sup>. Thus, the effective coordination of the various professional roles involved in organ transfer allows for Ontario and other provinces and territories to administer appropriate and (relatively) timely transplant services.

Nationally, Canada Blood Services (CBS), a not-for-profit charitable organization of which every provincial health minister is a funder and member, acts as the primary national registry and manager of the supply of blood and blood products in the country. However, as there has been a growing need for increased support in managing organ

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<sup>14</sup> The other seven OPOs in Canada are as follows: BC Transplant (also servicing patients from the Yukon), Southern Alberta Organ and Tissue Donations Program (located in Calgary) and HOPE (Edmonton) in Alberta (which also services patients from the Northwest Territories and Nunavut), the Saskatchewan Transplant Program (serving Saskatoon and Regina), Transplant Manitoba, Québec-Transplant, and the Nova Scotia Multi-Organ Transplant Program (which serves all of the Atlantic region including P.E.I.) (CIHI, 2011).

transplantation initiatives, CBS became one of the primary federal organizations involved in overseeing and improving organ transfer systems in 2008 (Canada Blood Services, 2011)<sup>15</sup>. At the same time, national associations have cropped up to aid in the sharing of information and best practices in order to improve knowledge and services on the ground; such is the purpose of the Canadian Society of Transplantation (CST) and the Canadian Society of Nephrology (CSN). Finally, the Kidney Foundation of Canada is a national charity designed to support and develop kidney-related research and policy, and, of course, similar organizations exist for all transplantable organs. Thus, Canada currently has an extensive and supportive network of organizations that are focused on improving techniques for organ procurement and sharing best practices within hospitals.

The state of Canada's organ transfer system is reflected in a few key statistics, mainly transplant and donor registration rates. In 2008, there were just over 36,000 people in Canada living with end stage renal disease (ESRD), which was an increase of 57 percent since 1999. Of those diagnosed with ESRD, almost 22,000 were receiving dialysis treatments, but only about 5,500 initiated "replacement therapy," i.e. where transplant became the next step in the process. In the same year, only 1,216 transplants were actually carried out (CIHI, 2011). According to a 2011 report published by the CIHI, diabetes was shown to be the "predominant cause of ESRD in Canada, identified in 34% of new cases in 2009" (p. v). The report also explained that "the aging of the Canadian population is reflected in the demographic profile of new ESRD patients, with 54% of those who initiated RRT being age 65 and older in 2006, compared to 33% in 1990"

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<sup>15</sup> In 2008, CBS merged with and took over the primary roles of the Canadian Council for Donation and Transplantation (CCDT). The CCDT was a not-for-profit agency at arms-length to Health Canada, which was established in 2001 by the Government of Canada, and tasked with addressing the growing shortages in Canada's organ supply that became apparent in the late 1990's (Norris, 2009). When CCDT had not made progress by late 2007, CBS took over.

(p.vi). In 2009, Canada reported having an average of 13 donors per million population (pmp). This number is low when compared to the United States, which tends to have rates hovering around 21 pmp (The Edmonton Journal, 2008). In fact, Canada is known as having one of the worst organ donor rates in the developed world. Overall, every year, approximately 2000 organ transplants are performed in Canada and about 300 Canadians die while on waiting lists (The Edmonton Journal, 2008).

Some argue that low donor registration rates are particularly problematic in that they may point to a general apathy among the population, or to a misunderstanding about what organ donation is and why it is important. A 2010 poll conducted by CBS found that, generally, Canadians are highly supportive of organ and tissue donation and agree that reducing wait times for people requiring donated organs and increasing awareness about donation both in the public and medical field are important. Still, less than half of Canadians have registered their willingness to donate their organs upon death and seven out of 10 cannot name the OPO responsible for donation registration within their province (Canada Blood Services, 2011). Such responses show a general lack of awareness among Canadian citizens and likely an overall apathy towards issues of organ transfer.

Interestingly, others argue that despite these low registration rates, there simply may not be enough organs to go around. Donation after brain-death (DBD) accounts for approximately 3.7 percent of all cases where donors may be obtained in intensive care units (MacDonald et al., 2008). Brain-death is considered the world standard for determining eligibility for donation; bodies are maintained through life-support machinery but there is no electrical activity within the brain stem. Organs remain in a living state but the individual will never regain consciousness. Brain-death diagnosis is

declining due to factors such as fewer fatal vehicular accidents, safer cars and less risk taking (Baer, 2007). Thus, Canada faces a number of challenges, including a general lack of awareness and apathy towards organ donation and transfer services, as well as fewer eligible donors as brain-death diagnoses decline.

In light of these shortcomings, Canada has developed initiatives to help address gaps in supply and demand. In November 2010, CBS announced the first living-donor exchange through a new national registry. The registry is designed to connect individuals with a living kidney donor that is not a blood or antibody match, with another couple who is similarly unmatched. The living donors then donate their kidney to the matching recipient of the other pair (Canada Blood Services, 2011). Thus, Canada has sought solutions for individuals who may have a live donor come forward for which they are not a match, thereby reducing the number of people waiting on lists for deceased donors.

Another strategy has been to include donation after cardiac death (DCD) into the normal transplant repertoire. With DCD, cardiac death has occurred, meaning that the heart has stopped beating for a particular amount of time; however, there may still be some form of residual brain function, thus donors do not meet the criteria for brain-death. Upon a family's consent, all life-support machines are removed, and if the person's heart stops beating within five minutes, the individual will not be resuscitated and is set up for organ removal (Cooper, Chin, Krieger, Fernandez, Foley, Becker, Odorico, Knechtle, Kalayoglu, Sollinger, D'Alessandro, 2004). DCD has increased the number of transplants in Ontario dramatically, with an additional 100 DCD donors being utilized in 2009-2010. Approximately 17 percent of all donations are now from DCD donors (Trillium Gift of

Life, 2011). Thus, expanding the definition of death to include DCD donors has been a fairly successful strategy for increasing the supply of organs.

Organs are also exchanged between transplant centres, which can increase the chances that an individual requiring an organ that is rare, such as an organ with Type AB blood, can receive one. For example, in southern Ontario, London Health Sciences may transport a kidney to St. Michael's Hospital in Toronto, which upon receiving the kidney becomes indebted to London Health Sciences and is expected to repay the kidney at a later point in time<sup>16</sup>. This is because the cost of sustaining a donor body until the time of organ removal is incurred in the hospital that is also losing a potential transplantable organ. Thus, a "repayment" system is in place to help balance these costs. Canadian hospitals also have the option of exchanging organs with hospitals in the United States; however, these relationships are different. While Canadian hospitals supply organs to U.S. hospitals free of charge, hospitals in the U.S. charge acquisition fees to the recipient hospital. In 2005, the fee for acquiring a heart from the U.S. was around US\$20,000. Though some program heads have noted this unequal relationship, whereby Canada is in effect helping to subsidize the American transplant system, there is also a general feeling against turning medicine "into a business" (Blackwell, 2006). Exchanging organs between hospitals is one strategy that can help to increase the number of available organs, especially in special cases; interestingly, however, there is a general sense that exchange must occur in order to balance costs.

Finally, one particularly powerful way that OPOs have sought to increase supply is through the heavy use of the rhetoric of gift giving. Though this will be discussed

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<sup>16</sup> The practice of exchanging organs between hospitals was learned during a discussion with a primary care nurse who explained the process.

further in the next section in relation to Healy's (2006) work, giving the "gift of life" is a particularly common sentiment used across Canada to pull at the heartstrings of people who prefer to view themselves as caring individuals. The Trillium Gift of Life Network in Ontario provides a particularly good example of the use of language to capture the hearts and minds of potential organ donors. In the spring of 2011, Trillium released a new website, "Beadonor.ca" that includes compelling video testimonials from transplant survivors who tearfully describe their illness and transplant experiences, as well as their difficulty in expressing their overwhelming thanks to donors and their families for the gift that they received. Beadonor.ca was created in order to promote and showcase a new online registration feature now available to Ontario citizens. In the past, organ donors were asked to "Say 'yes' to organ donation" by downloading and mailing a consent form. Visitors to the new site find the message "One donor can save up to eight lives," and are encouraged to "Register Now." These messages emphasize the impact of the "gift" of organ donation and encourage the act of affirming one's willingness to donate. They are designed to elicit positive feelings when it comes to thinking about organ donation. Of course, the reality is that organ donation typically occurs after sudden and terrible accidents, where a grieving family is approached to give their consent. Thus, organizations such as Trillium aim to show how something good can come out of something bad. Arguably, OPOs and their use of emotional messages are extremely important for changing the way that individuals view organ donation, such that it becomes seen as a positive activity.

Despite all of these initiatives and the various ways that organ transfer systems in Canada attempt to increase the supply of organs and reduce the suffering of people

waiting for donated organs, Canadians continue to participate in the international market for human organs, particularly for kidneys. This is because patients must inevitably wait, and even for those who receive a transplant, they are not necessarily at the end of their struggle. For kidney recipients, 10 percent of grafts will fail immediately, and up to 50 percent will fail within the first five years (Matesanz & Dominquez-Gil, 2007). Graft failure results in increased sensitivity to antibodies, thereby limiting the number of viable kidneys. Patients who experience graft failure often face an even longer wait time than was endured before their first transplant. Arguably, the longer one waits, the more desperate one becomes to find a solution, and turning to the international organs market is seen as a potential avenue.

In order to address this reality, in October 2010, the Canadian Society of Transplantation (CST) and the Canadian Society of Nephrology (CSN) released a policy statement expressing their position on organ trade and trafficking. In this statement, the societies condemn practices of commercialism. The recommendations provided in the document can be summarized as follows: a) physicians should provide pre-transplant counseling to patients on the dangers of travelling abroad to purchase organs, including the risk of “suboptimal care” and the exploitation of poor people, b) transplant professionals should not entertain relationships with clinicians elsewhere who are facilitating organ trade, c) physicians should not provide medications to those wishing to travel abroad for the time that they will be away, and finally d) as mandated by the Supreme Court of Canada, the release of medical records is up to the discretion of the primary physician who should not release documents if they believe the patient will come

to harm. Ultimately, this statement provides medical professionals with tools for mitigating the desire of their patients to travel elsewhere to obtain organs.

Overall, this analysis of Canada's health care and organ transfer system shows that, from an ideological standpoint, organs are indeed *contested commodities* (Scheper-Hughes, 2003). We can see this contestation echoed in our organ donation system. Organs ought to be procured from individuals who are willingly giving of themselves (or their families are) where there is no monetary exchange on the part of the donor or the recipient. In Canada, we rely heavily on the rhetoric of gift giving; we rely on and value highly the altruistic organ donor. Organs are gifts, they are special; they are not commodities. But of course, care costs money and there are significant interests that serve to direct the flow of funds and therefore affect the kinds of services that the system can feasibly provide. So, we can ask, are organs seen as commensurable in Canada (i.e. can they have monetary value)? The answer is yes, in that they are part of a highly bureaucratized legal-medical system containing both public and private interests, which are responsible for overseeing all aspects of organ transfer. This system is actually a multi-million dollar "business" where funds flow out of sight of its "clients." This system operates under the rhetoric of gift exchange, which some claim actually serves to disguise "the origins of commercialized body parts, silencing [...] the commodification process" (Sharp, 2000, p. 304). However, from the perspective of the public, organs are not commensurable, as the dollars attached to organ transfer are never seen or discussed. Thus, it appears that there is potential for confusion around what is exchangeable and what is not, and what forms of commodification are acceptable, according to when and

whom, and, thus, likely there is confusion around participating in exchanges for organs on both the part of medical professionals and patients.

In summary, access to healthy organs through transplantation as a core medical service is seen as a right in Canada. Canada relies on its opt-in donation strategy, as well as a number of other initiatives, to provide its supply of organs within its transfer systems; however, it continues to fall short of demand. Though there is persistent use of the rhetoric of “gift giving” and affirmative public campaigns to increase awareness and positivity towards donation, long wait times continue to compel patients to turn to the international market. So, from a public perspective, organs are not commodities, as the dominant procurement method continues to be through voluntary gifting; however, from an administrative perspective, organs are commensurable as they are directly tied to funds that must come from somewhere. Ultimately, the exchange of money for organs, or other forms of payment, is hidden from the public and may reflect a strong commitment to the ideal of social responsibility. Still, this creates confusion as market incentives are a component of not only the medical system, but of everyday life in a liberal capitalist state such as Canada.

As mentioned earlier, Titmuss sought to contrast cases where systems differ in order to create a scale of the forms of donation and the institutional arrangements that provide support for the particular motivations behind giving of the self. His argument was that values have a direct impact on the provisioning of health care services, which can be seen through an analysis of systems of human product procurement and allocation. His analysis focused on blood systems. On the surface, it appears that Canada’s organ transfer system reflects the “social responsibility” model that Titmuss supported, such

that the system is consistently based on altruistic, voluntary donation, and there have been initiatives taken and policies written in a clear attempt to maintain that system. Still, organ transplant is costly and there are other forces at work that create conditions where the body is indeed seen as a commodity. Thus, not only is there a mix of public and private interests at the level of health care administration, there is also a mix of values that see the body as simultaneous non-commodity and commodity. It is my contention that this may serve to confuse the waiting patient who perhaps does not fully understand the process of procurement and allocation, but who must wait for others to be altruistic in order to regain some semblance of a normal life. When others do not step forward, and, as mentioned, Canada's registration rates are low, it likely creates a certain amount of frustration. Desperation may drive Canadians to travel abroad to buy organs. And so, using transfer systems as a means to identify dominant ideologies within a society, as Titmuss claims, will not necessarily yield the most accurate description of what values are held in highest esteem. Importantly, this presents an opportunity to find alternative ways to undercover the dominant social values that both impact and are impacted by organ transfer systems.

As mentioned earlier, Titmuss' work is presented in this chapter as an anti-thesis to the critical perspective provided by Scheper-Hughes and others in relation to viewing the body as a commodity and the conditions leading to markets in human organs. Conceptually speaking, we can consider these two view points, Canadians as "consumers" on the one hand and Canadians as "altruistic" on the other (as reflected in our organ transfer system), as polar opposites. Scheper-Hughes argued for viewing the wealthy, mainly white Canadian as the potential organ buyer in a liberal capitalist market

that degrades all notions of humanness. On the other hand, Titmuss finds the common thread of social responsibility and universalism woven throughout the medical provisioning of modern welfare states, particularly those who support the voluntary donation of body products. The analysis of Canada presented here yields the following conclusion: though Canadians participate in the trade, their motivations and reasons for doing so are likely complicated by a few factors, one of which may be confusion around the simultaneous commensurability and non-commensurability of organs within organ transfer systems. The opposing poles as laid out here do indeed provide the extremes of the “consumer” on the one end and the “altruist” on the other. What seems to be the case is that Canadians fall somewhere in the middle, though it is unclear exactly what characteristics define this position. Uncovering the values that align Canada with both of these poles will be a challenge, and, as mentioned earlier, is the focus of this study.

In order to further solidify an understanding of the position of Canadian values in terms of organ transfer, the following section discusses some alternative viewpoints. Providing a conceptual balance between the extremes presented by Schepers-Hughes and Titmuss, economic sociologist Kieran Healy illustrates the need for a “middle ground” between the positions of market versus altruism. As such, the following section elaborates on alternative transfer systems, mainly incentivized donation, followed by a brief discussion of perhaps the most socially responsible, though arguably not altruistic form of organ procurement, the presumed consent or opt-out strategy.

***Addressing the Consumer-Altruist Polarization: Incentivized Donation and “Opt-out”***

This section focuses on alternative ways of organizing organ transfer, and seeks to address the polarization provided by Scheper-Hughes and Titmuss. First, Healy discusses the “cultural work” that organ procurement organizations (OPOs) perform, which maintains a commitment to altruistic donation as the best procurement strategy. He argues that this work will be even more crucial as OPOs inevitably switch to incentivized organ donation models as a result of continued organ shortages. Healy also highlights options for non-monetary (or hidden) incentives, such as covering the cost of funeral expenses for donor families, as well he highlights arguments for and against direct monetary incentives, such as paying cash directly to the living donor or donor family. Finally, one other alternative form of transfer system is presented, “opt-out” or presumed consent. Common arguments for and against its implementation are mentioned, as well as its effectiveness in countries that have implemented such a system. Opt-out strategies have been the focus of a great deal of discussion regarding improvements to organ transfer systems world wide.

In his book *Last Best Gifts: Altruism and the Market for Human Blood and Organs*, Healy (2006) presents an analysis of the American blood donation system generally, and blood and tissue procurement organizations more specifically, and how they have been affected by changing social values over time. Notably, he discusses the ongoing conflict between values that support voluntarism and donation, the persistence of market values in American society and the responsibility of OPOs to balance this conflict in ever more creative ways.

To begin, Healy argues that the reason why organ procurement is so controversial is that it relies on two socially and culturally “uncomfortable” facts: the definition and

calculation of the death of a potential donor, and the insistence on a “cash value” for organs. Healy states that despite discomfort with putting a price tag on our organs, the American system is comprised of a multitude of private entities (even more so than Canada) and, because of this, there must be exchanges of funds and repayments for goods received when goods are transferred between centres, clinics, hospitals and individuals. For Healy, the point is that patients and families must not be aware of the exchange, because if they are aware of it, a public statement is being made about the value of human life that people may not find appealing. He notes the “carefulness” that organizations involved in the transfer of human goods must employ in order to operate in a marketplace, but, at the same time, downplay its role. Organizations that oversee the procurement and allocation of organs are stretched, stressed by the unrelenting need for organs that are in short supply. This pressure, Healy says, leads to institutions becoming “culturally creative” as they try to make market-based systems seem more human and meaningful, such that “the new practice can be reinterpreted in a way that allows it to be incorporated into existing ritual and reconciled to existing understanding” (p. 40). Thus, Healy attributes the organization of organ transfer to the discomfort that people feel towards not only death, but also the commodification of bodies, which requires a careful management of public awareness.

This discussion of the “cultural creativity” that organizations involved in organ transfer perform is indeed indicative of what is happening in Canada presently, particularly given the earlier discussion about Trillium. However, Healy takes this one step further and argues that this cultural work provides an avenue for entertaining alternative procurement strategies that may be market-based, but would not appear to be

so on the surface. He claims that because of the constant pressure of organ demand, and because voluntary donation has thus far been unable to keep up, providing incentives to organ donors is not only a logical next step, but it is also inevitable. Importantly, he explains that should organizations begin to adopt an incentive model for donation, the exchange must appear on the surface to be “non-monetary.” For example, non-monetary (or hidden) incentives might include payment in the form of small reductions in taxes for living donors, or the covering of funeral expenses for deceased donor families paid directly to the funeral home. In this way, he says, institutions can avoid the public becoming aware of the relationship between money and organs, while being able to announce an increase in organ supply that is not the result of monetary exchange. The cultural work of organizations for procurement, then, would be to continue to mask the nature of the exchange enough to maintain the traditional values within what can still be called a “voluntary” organ transfer system.

The concept of non-monetary or hidden incentive is compelling in that the function of organizations involved in organs transfer, as culture generating apparatuses, is brought to light. Viewed through Healy’s lens of the historical impact of values on the organization of the transfer of human products, we can see how incentives that perhaps do not look like incentives could easily begin to circulate throughout systems that previously relied solely on the altruistic behaviours of others. Whether such a development is inevitable, however, is challenged by the fact that until this point, this has not happened, at least not in Canada. Canada does not have an incentivized donation system for organs. American blood, tissue and organ transfer systems are arguably different from Canadian ones and indeed have a long history of privatization and marketization. Though this will

not be discussed here, it is still important to note that incentives may or may not be a logical next step in the transfer of human products, and it has yet to happen in Canada.

Considering this argument for the inevitability of incentivized donation, others, particularly physicians, have shifted the discussion towards the implementation of direct monetary incentives or paid donation. Upon first glance, paid donation (if we can, at this point, still call it “donation”) is very similar to exchanges made through the international organs trade; there is an exchange between a buyer and a seller. It is also in line with the gift relationship that Mauss (1974) describes: an organ is “given” through an informal contractual agreement, it a socially purposeful act that is driven by the promise of a return or reward. It is also most closely related to Titmuss’ typologies of *the paid donor*, *the professional donor*, *the pay-induced volunteer* and *the fringe benefit donor*. However, incentivized donation is different from the current international market. In the international market, two rational economic actors look to benefit from an exchange of cash for an organ (e.g. a kidney for a dowry, corneas for debt repayment, half a liver for feeding a family, etc.), and because organ markets are illegal, they are inevitably pushed underground, making exchange dangerous for both desperate buyers and sellers. However, the most widely supported form of providing monetary incentives for donation involves the buyer role being taken up by the state itself in a regulated system. This type of system presently exists only in Iran. It is known as the Iranian model, which as a “state-sponsored, transparent, non-commercial, middleman-free kidney transplantation, whereby donors are paid by a government-sponsored agency, has eliminated the waiting list completely” (Daar, 2006, p. 600). There has been growing support for similar systems in Canada and the United States where demand for kidneys stands to increase over time.

Supporters argue that the benefits of paid donation are many (see Daar, 2006). First, potential donors can be screened with the full extent of the medical system<sup>17</sup> before being paid in full for their donation, which would avoid Titmuss' concern about the quality of organs from donors who may be exposed to disease, drug abuse, etc. Second, existing donation organizations can be utilized to coordinate the marketing and administration of paid donation, ensuring that all forms of quality assurance can be met to reach the current standard, such that the institutions currently assigned to the coordination of organ transfer would continue to do so with the same efficiency and quality. Third, the allocation of organs would remain anonymous based on need that is determined by the medical system, removing any chance for directed donation or favouritism on the part of the donor. On the other hand, skeptics claim that paid donation is unnecessarily and unjustly exploitative of those living in lower socio-economic brackets who would likely be the ones to donate (Schweda & Schicktanz, 2009). There are very strong voices on both sides because both aim to ease the suffering of desperate people; however, it is clear that whether it is an individual or the state buying a kidney, there is still a person being used as a means to an end. Looking back to the earlier discussion provided by Wilkinson (2003), we are reminded that treating the body of the other as an object that can be utilized for personal gain counters the fundamental moral principle of "human dignity," such that an individual has an intrinsic value and ought not to be used in order for another to profit. It is true that, in this case, the seller profits from the sale of his kidney; however, the organ transplant system also "profits" in its ability to provide organs to those in

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<sup>17</sup> Potential donors would undergo all the physical and psychological testing currently administered within transplant medicine, which would ensure that a donor is healthy enough and of sound mind to provide an organ.

need<sup>18</sup>. Thus, the prospect of incentivized donation through a regulated state-sponsored system is attractive because it provides a viable opportunity to obtain more kidneys with which to supply the growing demand.

Importantly, this discussion of incentives in organ transfer systems draws attention to a common theme that appears, in one form or another, throughout much of the work presented here, and that is the perceived *danger of commodification*. Healy describes this danger as follows, echoing similar statements made by Titmuss:

When applied to the case of human goods, the view suggests that we get what we wish for. If we talk of blood as if it were a commodity, then people will come to commodify it in practice. By instituting a market for blood or organs, people orient themselves towards these goods in a new way. The rational calculus of costs and benefits come to override alternative ways of thinking about the value of what is being exchanged. (p. 11)

The fear is that should human parts be considered like other common consumption objects, subjected to the forms of market interaction and rational, economic cost benefit analysis, then society loses sight of something more, something perhaps too complex to accurately explain, but something human and powerful. When considering incentivized systems of paid donation, whether payment is received from governments or individuals, the fear is compounded by the inclusion of institutions that support such practices. If institutions develop out of and through dominant values, and it is values of

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<sup>18</sup> Though it is beyond the scope of this paper, it is important to note that a discussion of bodily integrity is further complicated by the concept of “body as personal property.” When we imagine the body to be the property of the individual, the question becomes whether it ought to be an individual’s right to sell their own body, and organs, as he or she wishes. This is particularly relevant when one considers that other forms of body sale, like prostitution, are not prohibited in Canadian society.

commercialism that are reflected back onto a society, it may not only be seen as distasteful by some members of that society, but also threatening to the reproduction of positive social values. It is unclear at this time whether the danger of commodification is indeed a strong motivator and predictor of the continuation of purely voluntary, altruistic organ donation in Canada.

There is one other alternative strategy that is useful for addressing the polarization of consumption versus altruism, and for identifying Canada's position between the ideologically opposing camps, that is the presumed consent, or "opt-out" donation strategy (NSHBT, 2008)<sup>19</sup>. Presumed consent is thought to be the flagship model of the Spanish organ transfer system, but it is also in use by a number of other countries including, but not limited to, Portugal, Austria, Finland, Hungary, Norway, France, Italy and Poland. Interestingly, these systems vary when it comes to obtaining consent for donation. For example, all of these countries have legislated presumed consent; however, only in Portugal, Austria, Finland and Hungary is presumed consent carried out in practice (Cohen & Wight, 1999). Otherwise, these systems are considered "soft" opt-out because individuals and families retain the right of refusal on whatever grounds they deem appropriate. Thus, Norway, France, Italy, Poland and Spain abide by a rule of informed consent and right of refusal. When an individual is alive, refusal to participate in donation upon death is achieved through signing a legal opt-out document. When an individual is eligible for donation after brain or cardiac death, families are given the choice to donate their loved ones' organs, similar to what happens in Canada. If an individual does not have a family and they have not previously opted out, their organs

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<sup>19</sup> The implementation of opt-out systems has been discussed a great deal in Great Britain and many other European countries, particularly due to its success elsewhere.

will be donated. Currently, the rate of refusal in Spain is around 14 percent, which is an improvement from the early 1990's when that rate was closer to 30 percent (Miranda, Cañón & Cuende, 2001). However, a common argument is that the number of people who refuse to donate in Spain is far lower than the number of people who simply do not step forward to donate in opt-in systems (Organ Donation Taskforce, 2008). In 1998, Spain celebrated having the best organ conversion rate in the world (Bosch, 1998) and, today, Spain continues to be a leader in organ donation, with 35 donors per million population (pmp) annually. Because of the success of meeting organ demand in countries that have adopted presumed consent strategies, there has been considerable discussion about how and why such systems work, and how other countries could implement them in order to achieve similar results.

In keeping with the discussion thus far, it is interesting to consider the ideologies and values that are supported through having an opt-out system versus an opt-in system. Though there has been some discussion of the implications for a society that accepts such a strong role of government in terms of presumed consent legislation, social scientists have only scratched the surface of what makes these countries special from an ideological standpoint. Still, we can see that certain sentiments are communicated through a system that assumes all citizens to be donors, especially in countries that do not follow a rule of informed consent and the right of refusal. These sentiments might include a strong public commitment towards increasing the number of available organs for dying people. Also, health care providers who are similarly committed to the goals of such a system would not be seen as complacent when it comes to the needs of individuals with organ failure (Organ Donation Taskforce, 2008). Notably, these sentiments resonate with welfare state

social policy, in that they recognize the suffering (e.g. pain, fear, death, etc.) and injustices (e.g. poor health as a result of working conditions) that particular individuals within a society experience. Perhaps countries that adopt opt-out strategies show an overall stronger commitment to welfare state administration, as opposed to the more liberalized health care that is found elsewhere, such as in Canada.

In 2008, a group known as the Organ Donation Taskforce, organized by the National Health Service in the United Kingdom, released a report entitled *The Potential Impact of an Opt Out System for Organ Donation in the U.K.*. In this report, the taskforce identifies both the strengths and weaknesses in adopting a soft opt-out system. Despite the potential for increased organ supply, it was stated that “assuming consent from silence belongs to a more paternalistic era” (p. 5). Further, the report states that according to members of the public, it was felt that “an opt out system could be ‘dehumanizing’” particularly “given that current trends in healthcare place great emphasis on choice and responsiveness” (p. 5). These concerns, such as a reaction to the perceived threat of paternalism and the need for health care to continue to respect individual choice, are arguably reflective of a liberalized health care system. It appears that while opt-out provides another alternative strategy for organizing organ transfer, which may be able to increase organ supply significantly, it is likely that the social and political conditions that would allow such a system to develop are not present in the U.K., and arguably are not in Canada either.

What this analysis of the alternatives provides is an expansion on the context of the Canadian case in regards to systems of organ transfer, the underlying values that help to shape the administration of organs transfer, and the decisions patients make in regards

to accessing much needed organs. Canada seems to be at an impasse. If we consider the main theoretical arguments presented thus far, we find a partial answer to the broad theoretical question of this work, and that is, are we consumers or are we altruists? The answer of course is complicated. We see that the Canadian system is grounded in the dominant social values, ethics, morals, i.e. a dominant ideology, that creates ways of interacting within professional medical fields, sets the prices and rates for treatments and services and, ultimately, ensures the conformity of services to the expectations of those who demand and use them. Said simply, organ donation is viewed as the safest, morally sound procurement method. At the same time we are located within an affluent, Western, arguably privileged position, where markets prevail and interactions more and more take on the form of economic relations. Yet, we appear to be holding on to something that perhaps cannot, or we believe ought not to, ever be commodified; human organs are different. Still, Canadians participate in the commodification of bodies and organs every year in their participation in the international trade. But, this logical extraction and reworking of some major themes in the field of organ transfer systems and institutional organizations and values would be meaningless if we were to ignore the perspective of those who have experience dealing with such politically controlled systems. By capturing the perspectives of those dependent upon the system, whether for maintaining life (patients) or income (medical professionals), we can put this analysis of systems and values to the test.

## **Conclusion**

Canadians participate in the international market for human organs. They come to realize their role as “buyer” in a complex social, cultural and political nexus. Each of these factors shape patients’ experiences of waiting for donated organs and, therefore, significantly influence decision making when it comes to procuring a kidney for oneself. Arguably, the values that lead patients to choose the market are different from those that lead patients to prolong their suffering by waiting for a donated organ. Simply speaking, these represent two polarized ideologies when it comes to procuring organs: consumerism and altruism. Assuming that we can look to our current organ transfer system in order to identify the values that circulate within society generally, we can see that, indeed, altruism and a commitment to social responsibility appear to be dominant; however, patients continue to purchase organs abroad. This may be the result of confusion around when the body can be and is considered a commodity and in what contexts and by whom, especially given that health care in Canada is a mix of both public and private interest, and all services involve an analysis of cost. Such contradictory behaviour points to the complexity of not only Canada’s health care administration, but also to the complexity of patient decision making when it comes to coping with the inefficiencies of the system. Overall, what is missing in the literature is recognition of the real, lived experience of those who must make the choice between going abroad or waiting at home, as well as the voices of those who must help them in their struggle to survive. Importantly, this study seeks to incorporate those voices into the literature.

When the donation system cannot provide what it promises, perhaps patients are led to consider options that otherwise would never have been recognized as feasible. Given that Canada is a liberal capitalist country where individualism, consumer choice

and demand permeate every aspect of social life, perhaps patients would travel abroad if they are unable to get what they wanted at home. Or, perhaps Canadians are committed to their system of organ transfer and, despite their desire and financial ability to execute a trade abroad; they would never turn their back on a system that their country has agreed is the best, most moral option. So, in addition to the insights provided by the literature reviewed in this chapter, it is necessary to further consider Canadians' motivations and reasons for choosing one type of system over another, why they choose to stay or to travel abroad for organs. On the basis of the literature reviewed, it appears that in terms of the dominant values that are fundamental to this choice, Canadians fall somewhere in the middle of the two polar camps of consumerism and altruism. However, it is unclear exactly what the characteristics of such a position are, and how Canadians themselves define it. The next chapter highlights the methods undertaken in this study.

### CHAPTER 3: Methods

In order to answer the research questions of this study, there is a need to understand both the larger social structural forces that influence knowledge and behaviour, as well as individual interpretations that a) impact decision making when it comes to participation in the market for human organs, and b) influence perspectives about the current donation system. Berg (2008) discusses the varying definitions that have been used to describe and identify the practice of doing ethnography. He usefully explains that the common thread among them is the placement of researchers “in the midst of whatever it is they study” (p. 191). This definition conjures images of researchers who are physically and to some extent personally and emotionally involved with the subject matter of their work. Writing ethnography then becomes a matter of cultural description (Wolcott, 1999), an *etic* understanding, or outsiders interpretation, of the natural phenomena, to the best of the researcher’s ability. The main goal, however, is to provide an accurate representation of the experience of the “native inhabitants” of the field, in order to usefully contextualize and theorize from their very real, lived experience (Berg, 2008, p. 193-194). Thus, social scientists use ethnographic methods in order to gain an understanding of the social realities of those involved in the issue under study.

This study had two phases which form the ethnographic work conducted in order to answer the research questions. The first phase involved *participant observation* where I performed the duties of a volunteer within a dialysis clinic and observed the day-to-day activities of patients and nurses within the care environment. The second phase involved 12, 50-120 minute *semi-structured interviews* with participants from two key groups: *medical professionals*, defined as individuals working in various roles in the dialysis

clinic and varying structural distance from patients (i.e. ranging from those with the most patient contact to the least, from nurses to physicians, respectively); and *hemodialysis patients*, individuals waiting for kidney transplants through either deceased or live donation. This purposive sample included medical professionals and patients involved in kidney transfer, who were selected on the basis that: a) kidneys are in the highest demand due to the increasing prevalence of health conditions that often lead to renal failure, such as diabetes, b) kidneys are commonly donated from living individuals all over the world because it is possible to live with one kidney, and, as such, c) kidneys are the single most common organ involved in organs trade, and finally, d) patients on dialysis are more accessible than patients waiting for other organs. Patients on hemodialysis are able to participate in research because they tend to be more mobile and healthy than patients waiting for other organs such as lungs or hearts.

Additionally, the choice to interview six patients and six medical professionals was made based on the limitations of time and scope. Originally, an additional population was considered for this study: patients who had received a transplant at some point in the past. However, recruiting these patients would have required significantly more time on the part of the researcher as these individuals a) visit a post-transplant clinic that is separate from the dialysis clinic, and b) visit the post-transplant clinic infrequently as their care is geared towards follow-up procedures. Given that each interview involves planning and travel, time for the interview, which could range anywhere from one to two hours, note taking, transcription and analysis, it was determined that 12 interviews was a reasonable and acceptable number of interviews from which in-depth, relevant information could be drawn.

This study required ethics approval from two centres, the University of Guelph and the hospital where participants were recruited<sup>20</sup>. Clearance was only given by the University once the hospital ethics board had cleared the study. Medical professionals were recruited by email, phone or through face-to-face interaction<sup>21</sup>. The patients, being the more vulnerable group of study, were recruited through a number of methods that did not involve the researcher directly contacting patients, including: a) posters placed in and around waiting rooms and lobbies of the two dialysis clinics associated with the hospital, with information and consent packages attached; b) clinicians who spoke with their patients about the study, answered patient questions and encouraged patients to participate; and c) word of mouth. In many cases, clinicians acted as mediators between me and the patients, particularly in regards to scheduling interviews, which was mainly achieved through email. This meant that in most cases, I did not know the participant's full name nor any of their personal or medical information beyond what was mentioned during the interview. Additionally, these patients were selected by the care providers on the basis that they could converse, in English, on matters of the transfer system for up to two hours. Due to this form of recruitment, patients with reduced cognitive abilities as a result of illness or other factors, and patients with a low level of English language comprehension were not included in this study. Because patients were being dialyzed while the interviews took place, they were made aware that confidentiality could not be

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<sup>20</sup> The hospital, which was involved in this study, is located in southern Ontario and has a kidney transplant program. It also has two main dialysis clinics that serve patients in different geographic locations. Participant observation was carried out in one of the dialysis clinics, while interviews were carried out in the other.

<sup>21</sup> Interviews conducted with medical professionals were not the primary concern of the hospital's ethics board. Rather, patient confidentiality and protection were the foremost concerns. Yet, medical professionals were included in the ethics write-up both for the University as well as the hospital.

guaranteed in that setting, since dialysis clinics are wide-open, shared spaces; however, this was not deemed to be a problem by the patients. Once the data were collected, participants were assured that they would receive the appropriate level of confidentiality as agreed by the researcher and ethics boards.

*Phase 1: Participant Observation* was conducted in order to address my need to understand the characteristics of the care environment, the nature of the interactions among people who work and seek treatments within it and, importantly, to become acquainted with the context, language and common activities of my research participants. This was achieved by serving as a volunteer for approximately 70 hours, over a four-month period. The primary role of a volunteer in the clinic is to help patients get around the hospital and provide them with water, ice, food, blankets and friendly conversation. This position was obtained through the volunteer services office and my intentions as a researcher were openly discussed with the volunteer coordinators. It is important to note that ethics approval was pending during the time that this phase was being conducted. Though a personal diary of experiences was kept, no records of any specific participant information were retained for use in this study and, as such, detailed notes will not be drawn on directly for the remainder of this analysis. Overall, this observer-as-participant work allowed me to become aware of and sensitive to the issues and concerns of my participants.

Broadly speaking, what was learned throughout the participant observation phase was how the characteristics of both the patient and the clinic can impact the illness and treatment experience. Patient characteristics such as average age, previous illness, severity of disease and subsequent physical and psychological damage determine whether

a patient is placed on a wait list or not. For example, many patients in the clinic were not on the kidney wait list due to their advanced age or current and previous afflictions with certain types of cancers. Similarly, characteristics of the clinic can impact how patients' experience the process of receiving care. For example, lags in hospital transportation services often resulted in elderly patients sitting in hospital lobbies for hours after undergoing dialysis. This volunteer position became increasingly valuable during the recruitment process as it showed potential participants that I had a more intimate knowledge of the challenges that can disrupt an otherwise "normal" day in the clinic.

Berg (2009) warns that it is not easy for new researchers to hone the skills required of them for conducting successful interviews. Importantly, the knowledge that I gained while volunteering and being able to share that I served as a volunteer, provided me with the confidence and ability to converse with ill patients in the care environment comfortably, ensuring that my participants did not feel uncomfortable speaking with me as an "outsider". As a result, I was able to obtain intimate and personal information from my participants, as I showed that I was able to speak to both the more technical components of care and also the lived daily activities of dialysis patients that would not be apparent to researchers who have never been inside the walls of the clinic.

*Phase 2: Semi-structured Interviews* provided the subjective experiences and perspectives that inform an analysis of decisions, concerns and constraints within organ donation systems. Semi-structured interviews are often used as a tool for "investigators [who] are interested in understanding the perceptions of participants or learning how participants come to attach certain meanings to phenomena or events" (Berg, 2009, p. 110). In total, 12 semi-structured interviews were carried out with two groups involved in

kidney transplant; as mentioned, these were *medical professionals* and *hemodialysis patients*.

Of the six medical professionals interviewed, three were nephrologists<sup>22</sup>, one was a primary care physician working in the clinic, one was a nurse manager, and one was a nurse who trains patients and their families in home dialysis. All physicians were male and those in various nursing roles were female. Of the six medical professionals interviewed, only one was not affiliated with the hospital from which all other participants were recruited. An important participant characteristic that is relevant to this analysis is the ethnicity of the participants; assuming that second, third or higher generations of Canadians may be more likely to adhere to core Canadian values than recent immigrants or foreign nationals. In terms of the ethnicity of the medical professionals interviewed, one was born in a south Asian country while the other five appeared to be at least second generation Canadians. In the following chapter, medical professionals will be referred to by number, as Professional (Prof.) 1, 2, 3, 4, 5 or 6, in order to maintain confidentiality.

Of the six waiting patients interviewed, all were receiving hemodialysis in the clinic at the time of the interview<sup>23</sup>. Three patients were “pre-transplant,” meaning they were waiting for their first kidney transplant. Of these patients, two were training for home dialysis, while one preferred dialyzing in the hospital; two had family members being considered for live donation, while one was on the wait list for a kidney-pancreas transplant. The other three patients were “post-pre-transplant,” meaning that they had

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<sup>22</sup> Nephrologists are physicians responsible for the diagnosis and management of kidney disease and related illness.

<sup>23</sup> Hemodialysis involves filtering the blood outside of the body through a machine that cleans it of toxins that have accumulated as a result of low or no kidney function. This is elaborated on in the next chapter in the Dialysis section.

received a kidney transplant in the past and, following rejection, they were placed back on dialysis and were waiting for another transplant. Of the post-pre-transplant patients, one had a family member being considered for live donation, one was on the wait list, and one was waiting for technology to improve due to the difficulty in finding a matching kidney. In all there were two female patients and four male patients interviewed. As will be discussed later, the age of the waiting patients was an important factor in how patients talked about the donation system, markets, and “Canadian values.” The ages of the patients ranged from 18-74 years old, and consisted of the following: 18, 33, 36, 40, 63, and 74 years of age. Similarly important, though not necessarily related to age, is the ethnicity of the patients; again, assuming that second, third or higher generations of Canadians may be more likely to adhere to core Canadian values than recent immigrants or foreign nationals. Although not all patients were Caucasian, all spoke English fluently with no recognizable accents, and based on conversations involving family members and their role in their lives, it appeared that most patients were at least second generation Canadians. Of the six patients, four had a life-long illness that they knew would eventually lead to kidney failure, and two had sudden, unexpected onset of kidney failure. Co-morbidities such as heart disease and high blood pressure were common among all patients, which is the case for most patients with renal failure. The length of time that the patients had spent on dialysis (since last transplant rejection for post-pre patients) ranged from 16 months to 8 years. In the following chapter, patients will be referred to by number, as Patient (Pat.) 1, 2, 3, 4, 5 or 6, in order to maintain confidentiality.

In terms of data collection, those awaiting kidneys were asked to provide information regarding their decision making process and their feelings towards donation

versus alternative procurement systems, such as purchasing organs internationally. Medical professionals were asked to provide information in terms of their understanding of the current issues on donation and procurement, as well as their thoughts on the international organs trade and the participation of their patients in it. Most of the questions were the same for each group, but phrased appropriately given the participant's relationship to organ transplantation generally (see Appendix B for interview guides).

Overall, the qualitative data were interpreted and analyzed with an aim to finding common themes and sentiments that answer the research questions. NVivo 9 software was used to organize data into thematic categories that emerged from the participants' responses.

## CHAPTER 4: Findings

The following presents the perspectives of patients and medical professionals involved in processes of kidney transfer in Ontario, Canada, specifically those who are currently either on hemodialysis and waiting for a donated kidney, and those who provide their care within the clinical environment. Perspectives are provided on a variety of issues relevant to both the literature presented in the previous chapters, as well as those deemed relevant by the participants. It is necessary to point out a perhaps unsurprising observation, which was that patients and medical professionals talk about issues of organs transfer and trade differently. This difference may be understood as the result of the lived experience of illness and treatment on the one hand, and the lived experience of administering care on the other. Although ideas and opinions often overlap between these two participant groups, the following discussion generally separates their responses in order to identify and contrast key themes. Overall, this section presents information that is highly relevant to a discussion of values in organs transfer and participation in international markets for human organs, as it brings to light the lived experiences of those who currently operate within the organ transfer system in Ontario.

Findings are divided into three main topical categories in order to answer the research questions. First, contextualizing the lives of patients waiting for donated kidneys and the work of their caregivers is achieved through a discussion of treatment options, *Hemodialysis* and *Transplant*. Importantly, these sections provide insights into the challenges that exist for people who need a kidney transplant. Second, three related subsections covering participants' perceptions of Organ Transfer Systems are presented and include *Opt-in*, *Opt-out* and *Incentivized Donation*. These sections highlight

participants' perspectives on the effectiveness of the current transfer system as well as their perspectives on the effectiveness of alternative systems. And third, perspectives regarding the *International Organs Trade* are presented along with a discussion of participants' opinions on the practice of purchasing non-transplant medical services abroad, or medical tourism. This final section demonstrates the degree to which participants are aware of and concerned about others involved in the trade in human organs, as well as the conditions under which patients participate in the trade.

## **Context**

### ***Hemodialysis***

As discussed in earlier chapters, a common explanation for why patients become organ buyers is that their own transfer system is unable to supply enough organs, creating long wait times. Arguably, time spent waiting for patients with renal failure does not necessarily equate to a negative experience; however, for most, time spent waiting means waiting on dialysis. Dialysis is many things for the people who must endure it, and this section is focused on explaining what dialysis is, what it means and how patients cope with the reality of “sustaining,” as opposed to living, on life-support. The following details the processes of hemodialysis, how patients feel about being on dialysis, the difference between how patients who dialyze in the clinic feel versus those who dialyze at home, how patients and medical professionals view the clinic as “family” and “community” and, finally, how dialysis is seen as something to be endured in order to reach the ultimate goal, transplant.

For patients experiencing renal failure, there are three treatment options: hemodialysis, peritoneal dialysis and transplant. As mentioned, this study is focused mainly on those who are currently involved in processes of hemodialysis. Hemodialysis is typically administered in outpatient facilities, meaning that patients come into the clinic, receive treatment and leave; however, home hemodialysis is growing and will be discussed later. Stated simply, hemodialysis involves filtering the blood as a kidney would, but outside of the body through a filter called a dialyzer and with specially formulated dialysate, which is a liquid solution that targets particular molecules. This process cleans the blood of toxins that have accumulated as a result of low or no kidney function, because patients are unable to produce and excrete urine. As such, patients generally feel unwell, fatigued and have a low appetite building up to the time when dialysis occurs. Blood is constantly taken and replaced through either a central line that is inserted directly into the vascular network around the heart, where tubes with attachments for hooking up the inflow and outflow lines stick out of the chest, a central venous catheter (CVC), or the flow lines are attached through needles inserted into a fistula in the arm. A fistula is a surgically created passageway made by attaching an artery (blood flowing away from the heart) to a vein (blood flowing toward the heart), in order to strengthen the vein, making it capable of handling repetitive needling. Once the vein has strengthened, which can take months or even up to year, needling is done in such a way that waste-filled blood flows out of the body and clean blood flows into the body at about the same rate, through a site typically located in a patient's forearm. If a patient's veins are too small or weak, synthetic ports may be inserted under the skin to provide the necessary pathways; however, these are not seen as the best solution due to the likelihood

of the body rejecting the foreign objects. The amount of time and dialysate required to effectively clean a patient's blood depend on their size and residual kidney function. Hemodialysis can be performed in the clinic or at home, and can take anywhere from two to four hours, or up to eight hours if a patient is dialyzing while sleeping (nocturnally). And so, most patients experience surgical pain as well as repeated pain with the insertion of needles on an almost daily basis. Additionally, they experience repetitive needling and run the risk of infection at the surgical and connective sites. Patients must also be extremely careful in terms of their intake of water and salts, and their dietary restrictions are many. It is also important to note that dialysis is not a cure, it is a treatment option. It is indeed "life-support" (Prof. 6) and is not designed to cure renal failure. Thus, there are many negative aspects of dialysis.

When asked how they felt about being on dialysis, patients who were regular visitors to the clinic expressed strong negative feelings, making statements such as "I hate it. I hate every minute of it. I hate coming here... Every time I leave the house and I come in, including this morning, I said "I HAVE to go now" I hate going here" (Pat. 3). Patients explained that being on dialysis is like being "in purgatory" or being "incarcerated" and that you "live to sleep." The reasons why patients feel this way about dialysis are many and include, to some extent, the factors of pain and the risk of infection mentioned above. However, other key factors include generally feeling unwell and extremely tired, falling behind in school, losing employment and the associated income and independence that come with working, missing time for family, scarring associated with multiple fistula failures, being unable to travel, and losing time for other activities. The inability to travel was particularly distressing for older patients who felt that they had reached retirement,

but had been cheated out of enjoying it because they were “attached to a machine” (Pat. 5). For example, Pat. 3 explained:

We’ve planned our whole lives. We have no family no children or anything...we wanna travel...Since I’ve been on the dialysis, I can’t go anywhere. So we get very frustrated sometimes at home because we have to stay at home.

The difficulty patients have with being attached to a machine was similarly reflected in comments made about feeling a lack of control. Interestingly, the concept of lacking control and how this impacts negatively on the emotional lives of patients was identified by medical professionals and not directly by the patients themselves. Medical professionals also pointed out both the social and emotional hardships that dialysis can cause. For example, one medical professional said the following based on his experiences with patients:

They have a horrible quality of life. Dialysis is not just a medical issue...they lose their job - it’s a social nightmare - they have to go on welfare sometimes, they have difficulty with their spouses, the medical issues cause difficulties in the way they function with their family - it’s a total nightmare - people get divorced. (Prof. 3)

Similarly, medical professionals pointed out the negative social and physical impact that co-morbidities can have. Co-morbidities, such as heart disease and cancer, are common among patients with renal failure, and often patients who enter the transplant program are already on a number of medications. Medications such as those used to treat hypertension can be extremely hard on patients and their bodies. For example, alpha-beta blockers to relax arteries can cause depression, diarrhoea, skin rashes and swelling (Scherer, 2011).

These side effects often make patients' illnesses worse over time. Overall, dialysis is perceived as an extremely negative, painful and disruptive activity insofar as it disrupts individuals' plans for their lives and stops them from taking part in desired and necessary activities. This is especially true for patients who receive dialysis treatments regularly at the clinic.

One unanticipated feature of the dialysis clinic worth mentioning was the acknowledgement of the care environment as being a "family," "community" and "culture." The "family" and "community" that the dialysis clinic represents for patients appeared regularly when patients would talk about their own experiences as well as those of other patients. For example, Pat. 6 stated:

You come in you have your routine. I come in I stop off and see B in pod one and W, she's always got plums and magazines for me and then you go to pod three and there's W and her mom and it's a little family. It most definitely is a little family.

Additionally, it was common to hear similar sentiments among medical professionals who stated things such as "They do look at this [as a] second home and they will all tell you that. This really is their second family" (Prof. 5) and "Dialysis is a culture... [my patient's] entire social structure revolved around coming to dialysis, meeting his friends and chatting" (Prof. 3). Interestingly, despite the social opportunities and family-like qualities of the clinic, it did not appear to be enough for patients who ultimately felt that living on dialysis is a horrible existence. For example, when asked if she would miss her dialysis community when she receives her transplant, Pat. 4 said "Not at all." This is important to note as it is unlikely that the sense of belonging and community that the

clinic provides is enough to mitigate the personal turmoil that patients feel and it is also unlikely that it is weighed significantly in their decision to go through with a transplant.

As mentioned, not all patients dialyze in the clinic, some dialyze at home, typically requiring the help of loved ones and typically while the patient is sleeping, also known as nocturnal dialysis. Interestingly, patients who dialyze at home (who were training on new machines when I visited the clinic) tended to express more neutral attitudes, greater acceptance and in some cases more positive evaluations of dialysis overall. For example, Pat. 5 said “we’re not happy with dialysis, but we live with it and our spirits are good. We feel reasonably good most of the time”. Similarly, Pat. 2, who was in fact able to continue working and maintain a relatively “normal life” expressed the following:

It's just one of those things you have to accept right? I mean, the alternative is death. I feel great and it doesn't interfere with my day because I have to sleep anyway so I do it at night while I sleep...I don't wanna do it for the rest of my life but to me it's what you make it.

Home dialysis is highly supported in the medical system because it is significantly less expensive than dialysis in the clinic. When patients dialyze at home they, their spouse or another family member, perform the activities that nurses would normally perform in the clinic, for example, needling, setting up and resetting machines, sanitizing stations, and paper work. Also, patients who can successfully dialyze while sleeping are often able to work normal hours and to spend time with family; therefore, they are more likely to be active participants in society. These comments serve to illustrate the potential that home dialysis holds for mitigating the negative feelings that patients have towards their

treatment, especially in regards to their enhanced sense of independence. Overall, patients who dialyze at home appear to have more positive evaluations about their treatments than those who dialyze in the clinic. This is likely the result of not having to go back and forth to the clinic throughout the week and the potential for enhanced independence and freedom from medications.

Despite the fact that patients who dialyze at home report having a more positive outlook towards treatment, home dialysis is not for everyone. Some patients who dialyze in the hospital do so because they do not want to go through the hassle of setting up their home for the dialysis machine. Others dialyze in the clinic because they do not want to have the constant reminder of the pain and discomfort of their illness while they are relaxing at home. Furthermore, the process of switching to home dialysis involves a home visit from specialists who inspect the home to ensure that dialyzing is possible and will be safe. A charge nurse investigates whether or not the patient has the available resources to dialyze at home and technicians investigate where the necessary utilities are available in the home, and, thus, determine which rooms are options for setting up the machine. One patient explained that although he had intentionally built his house knowing that in the future he would want and need to dialyze at home, he mistakenly only accounted for the additional electricity needed to run the machine and not the water hookup. Thus, for him, dialyzing at home would have meant further modifications to his built home and he did not want to go through the hassle and extra cost. This leads to another important note on home dialysis.

Currently, patients must either pay for the additional cost of water and electricity that dialyzing at home requires, or they must lobby their local government to help them

cover the financial burden. Fortunately, a few medical professionals mentioned petitions they have worked on and submitted to the provincial government to help people implement home dialysis. Still, as it stands, it is highly unlikely that people who have limited or low income, such as those receiving disability support, are able to cover the costs of bringing dialysis into the home. Not being able to afford home dialysis is a significant issue when one considers the potential benefit of the activity. Not only is it a cost consideration for the health care system, and thus more beneficial to have people dialyze at home, there also appears to be a higher employment rate among home dialyzers. Not to mention that patients who dialyze at home seem to experience less anxiety as a result of a greater sense of acceptance of their situation. Medical professionals recognized this inequity and are working to address it.

It is also important to note that in addition to financial cost, home dialysis also requires support, someone other than the patient who can help with certain aspects of care<sup>24</sup>. This is because often the location of a fistula in the upper arm area or central venous catheter (CVC) makes it extremely difficult for patients to needle or connect themselves. Thus, if someone is living alone, it makes it more difficult to dialyze at home, and, in most cases, it is not possible. Whether or not home dialysis is an option will therefore depend on the situation of the patient. Their ability to maintain their marriage or intimate or familial relationships thus becomes a significant factor for patients.

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<sup>24</sup> For example, respondents who dialyze at home tended to be married. Their spouses were present at the time of the interview as they were being trained in the clinic to use new home dialysis machines. It became clear during these interviews that without their partner, patients would probably not be able to do home dialysis on their own.

Also, the safety of home dialysis is likely the most significant issue when determining its value. One patient explained his near death experience while dialyzing at home as the result of not properly securing a needle:

The machine didn't shut down, so this needle came out and that was my fault because I didn't tape it properly and the machine kept running and didn't recognize it and was pumping my blood out...Fortunately my arm was on my chest at the time so I felt the warm blood seeping through my night shirt and I hollered at [my wife] and tried to stop it...we were lucky...there was so much blood all over. (Pat. 5)

Such risks of home dialysis likely lead some to question whether it should in fact be practiced. Home visits from clinical staff are not frequent in the sense that once a patient is set up, they only visit at infrequent intervals. The absence of trained professionals is likely a significant detriment to ensuring a high level of safety.

Finally, it is important to note that dialysis, whether in the clinic or in the home, is typically regarded as a stepping stone, an inconvenience to be endured until transplantation. As one patient explained when referring to his time on dialysis leading up to transplant:

I wanna get out of here. I wanna get off this damn thing. I wanna go out and live my life. But, I can't really do that when we're here 3 or 4 times a week...you're sort of in purgatory until it happens. (Pat. 1)

Another patient looking forward to a live kidney donation from a family member stated that she did not want to go on home dialysis, despite the benefits, because it was her hope that she would not have to be in the clinic much longer. Thus, many patients expressed

similar feelings that dialysis was something that would eventually end in transplant, which made them more capable of enduring treatment. Unfortunately, patients can expect to wait up to “3-5 years at least” (Prof. 4) for their first transplant and longer if they have received a transplant in the past. This is because when a body rejects a new kidney, it builds strong antibodies that attack the next new kidney, making chances of success significantly lower with each try. Much of the wait time required for a second or third transplant is due to the need to match the kidney as closely as possible in order to avoid antibody effects. One medical professional described how blood type and sensitivities impact the length of time patients wait:

The average wait list would be about 4 years for blood group O, the blood group B [is about] 3 years which is a bit of a surprise but that’s actually good news, and the As hover around the 4 year mark...Patients who are sensitized are a different thing altogether...those people can wait up to 10, 12 years, you know. (Prof. 2)

Overall, dialysis may be seen as endurable only insofar as there is some guarantee of it ending. For those with strong antibodies, a rare blood type or other physical abnormalities, the wait can be a significant length of time. Arguably, an average of four years is still a very long time to be experiencing all of the negative elements associated with being on dialysis.

In summary, patients who receive dialysis in the clinic have extremely negative perceptions of their diagnosis, and being on dialysis is likened to being in prison. The challenges that exist for those waiting on dialysis are many. Although the clinic can provide support for patients who come to see it as a community, a supportive environment does not appear to be enough to dissuade their desire for transplant and getting out of the

clinic. Interestingly, those who dialyze at home tend to have more positive attitudes and seem to feel better day-to-day, especially if they dialyze nocturnally. Still, there are barriers to patients who wish to implement home dialysis, including cost and the requirement of a person to administer care in the home. Some also feel that it is simply too much of a burden and yet others identified the potential dangers in not being in a clinic with trained staff to help. Ultimately, dialysis is seen as a burden that will inevitably be lifted, such that life can and will return to normal once transplant has occurred.

### ***Transplant***

As mentioned, transplant is listed as one of the three options for treating kidney failure. Like dialysis, transplant is not a cure but rather a treatment option that can lead to having a better quality and quantity of life. The following section identifies what transplant is and how it is organized generally, what transplant means to patients and the challenges that medical professionals face in dealing with patient expectations. Finally, it discusses some of the common fears patients have about transplant, particularly in regards to taking immunosuppressant drugs.

Kidney transplant involves replacing a non-functioning kidney with a functioning one obtained from a donor. Eligible recipients must maintain constant vigilance, particularly in terms of their physical wellbeing and not travelling far, in order to be ready for transplant at any time. Kidney transplant involves abdominal surgery to connect the new kidney with major arteries and veins, as well as the ureter (carries urine to the bladder), although the old kidney is typically left inside the body unless it is causing

harm, such as infection. The incision is approximately 15 cm across and is located on a patient's side, just below the rib cage. The surgery is relatively simple; however, because of the risk of infection, the chance that the body will reject the new kidney and the various consequences of the immunosuppressant drugs that patients receive post-transplant, patients are thoroughly evaluated to determine that they are physically and psychologically capable of handling the potential harms. If a patient is deemed eligible for transplant, they are placed on a waiting list that is organized based on a few key factors, which include age, blood type, length of time already spent waiting, and the severity of need. Matching donors to recipients also depends on the blood type, size and age of the kidney being donated. In the case of DBD or DCD, matching is coordinated through Trillium, which gives priority to patients within the centre that removed the kidney. If a recipient is not identified within the hospital where the kidney was removed, Trillium then calls other centres and offers it to an eligible recipient there. The quality of the kidney being transplanted is dependent upon the abilities of physicians and surgeons to identify potential imperfections that increase the risk of rejection in the recipient. Imperfections include potential problems related to the lifestyle of the donor, such as use of tobacco, poor diet, etc., as well as obvious visual imperfections such as scar tissue and lesions. Patients are on call 24/7 and must be able to come in immediately for surgery if a match has been found. Because of this sudden nature of transplant in many cases, it is necessary for physicians to keep up-to-date records on their patients' health. For patients who are arranging live donation through a friend or family member, the process is planned ahead of time; however, there are similar matching screens and procedures, and in fact rigorous psychological testing is performed on the donor to ensure that they are of

sound mind and are giving a kidney without being coerced. All patients must maintain constant vigilance when it comes to taking care of themselves so that they can continue to be considered eligible for surgery.

When asked what transplant means to them, all patients said “freedom.” More specifically, freedom meant freedom from dietary restrictions, from being attached to a machine and from medication. For older patients, transplant meant enjoying retirement; it meant time for and ability to travel. And for many, it meant time for family. One mother even said:

Just freedom. I mean, I have a 12 year old son. I leave here, I go home, I'm tired, he gets home from school, I'm sleeping, he goes to bed, I get up 'cause I don't sleep at night and so I never see him. I don't get to do anything with him, I can't go anywhere, I have to use a scooter because I get tired very easily...[I wanna] get this line out of my neck, I wanna go swimming with my son. (Pat. 6)

For patients, freedom from dialysis meant another chance at life; a chance to do all of the things that they are unable to do while they are sick and waiting for a transplant. The discourse of “waiting,” such as being on the “waiting list” contains similar sentiments, such that patients are not living on dialysis, they are waiting. One medical professional described it as follows:

They often have high expectations of a transplant, they have lower expectations of dialysis saying that you know ‘I need to survive to get the transplant’ ...all of a sudden they will return back to their glory days...And that's not a realistic expectation. (Prof. 3)

It appears that transplant is seen less as a treatment option and more as a cure as patients tie their hopes for the future to its success. Although equating transplant to a cure may make dialysis more bearable, it is not realistic.

Medical professionals play an incredibly important role in terms of mitigating the expectations of their patients and “bringing them down” (Prof. 3) to the reality of the situation. For example, Prof. 1 discussed the 10 percent rejection rate for patients who receive kidney transplant and other consequences:

It’s a problem ‘cause [transplant is] a huge help for those that are helped and for those few, it’s a disaster. And families get really upset...People don’t expect to die...1 time out of 10 you either die or it doesn’t work....and there’s lot of people involved...lots and lots of planning, lots and lots of expectation.

The “realities” of transplant are particularly salient for medical professionals who are used to relaying information to patients about the risks and spending time addressing patient expectations. Still, it is hard for medical professionals to ignore the potential for a better life that “9 times out of 10” transplant can provide. Medical professionals are thus in a difficult position because transplant can be very beneficial and it is their job to improve their patients’ lives; however, the way they treat transplant often serves to create a stronger demand for transplant among patients, and a belief that it will cure them. For example, one nurse explains that often medical professionals “put transplant on a pedestal” perhaps to the detriment of patients:

We say ‘when you get your transplant’ a lot. So I think we do put it up on a pedestal and maybe that’s where they get this feeling that this is the be-all-end-all,

and, maybe we don't always say 'it's a great option but it's not always optimal' ...everyone's looking for a good end, a silver lining. (Prof. 5)

In addition to highlighting the role of expectations in perceptions of transplant, this comment also illustrates another key point: transplant is not always the best treatment option and the risks are high. Many patients "do well" on dialysis, meaning they function well in their lives and feel good, and, thus, dialysis may be better than transplant. This became clear when nurses were discussing their elderly patients who had opted for transplant rather than staying on dialysis. For example, Prof. 6 explained:

I've said several times to my coworkers 'they (a patient in their 70's) would have been better off never transplanted' because things have not gone well. I think people are so focused on being off dialysis that sometimes they don't pay as much attention to the risks of transplant.

The fact remains, patients "hear what they want to hear" (Prof. 5) and many wind up worse off than they were before they were transplanted. This is the result of the interplay of expectations and desperation that patients feel when it comes to receiving treatments for end stage renal failure. Overall, medical professionals are particularly aware of the ways in which patients are influenced and feel drawn towards transplant; however, they are often complicit in that process. And despite the fact that transplant is not a cure, patients, in many ways, view it as one.

Of course, some patients do express certain fears when it comes to transplant; however, they are generally outweighed by the perceived benefits. Fears include failure, pain, more hospital visits, and, most commonly, fear of medication. The immunosuppressant drugs, such as prednisone that post-transplant patients must take for

the rest of their lives, have side effects such as hair loss or growth, acne, lymphoma, diabetes and stomach ulcers. In some cases, the drugs can have psychological impacts such as severe depression. Part of the information sharing that medical professionals do is designed to instil within patients the need to be committed to the process of transplant, including taking drugs. From the medical system's perspective, a patients' commitment to a drug regime is necessary in order to reduce waste and save costs in the future. From a patient's perspective, it can lead to second-guessing. Pat. 3 explained:

If you stop and think about it then your mind can really start racing... You have to make a decision...and the way they talk, they want 100% success rate. They do not want any failures...the failure usually comes in the patient after the fact. So they say 'you've gotta be aware and know that you wanna go through with this. It won't be easy...I've had second thoughts sometimes.

And so, there is pressure put on patients to maintain their health after transplant, and they are told that transplants fail because patients do not fully commit themselves to the drug, diet and lifestyle regimes that doctors set out for them. Based on similar discussions with patients, it appears that this pressure generates a certain amount of fear pre-transplant. Patients feel apprehensive about their ability to cope with the damaging effects of medications, and, therefore, the potential for them costing the system and themselves a much needed and valuable kidney weighs on their minds.

One other considerable outcome that perhaps patients and decision makers do not realize is that post-transplant, patients do not necessarily become fully active members of society. Based on discussions with medical professionals, this appeared to be the result of the co-morbidities that patients develop or that get worse while on dialysis, such as

cardio-vascular disease. Even after transplant, patients with such co-morbidities tend to remain on government subsidized incomes. Importantly, it was mentioned that often people who experience kidney failure and related co-morbidities, tend to come from low socio-economic groups and tend to have lifestyles that are detrimental to health over the long term, such as tobacco use and poor diet. Though this arguably is the focus of another analysis, it is important to note that just because a patient has been transplanted, it does not remove or fix the damage done prior to, during and after receiving a new kidney. Yet, despite this supposed trend, of the six patients interviewed for this study, two were continuing to work full time, one worked full time until recently and was looking forward to returning to work post-transplant, one was of high-school age, one was retired, and only one did not work prior to being placed on dialysis and was receiving income subsidies. Perhaps this sample is not representative as patients were chosen by nurses, partly based on their ability to converse on matters of the medical system for up to two hours. According to the medical professionals interviewed, the family history and socio-economic status of patients that are on dialysis appear to be predictive of a patient's level of involvement in society post-transplant. Not all patients are (re)incorporated into society following transplant as many will continue to struggle with illness, an outcome that seems to counter the perceived strength of transplant that patients will "return" to society.

To summarize, though transplant is one of three treatment options, it is ultimately considered to be the goal of treatment. Luckily, nine out of 10 patients who receive a transplant do not experience immediate rejection (though they may at some time in the future) and many are able to enjoy the various forms of freedom that patients identified. However, for those who do experience rejection, it can be devastating. Because of the

risks associated with transplant, medical professionals are aware of and work to mitigate the expectations of their patients; however, it is difficult for them to do so without imparting a positive view of transplant. Everyone wants a patient to get better. Still, transplant is costly and can be costly if organs fail; there is a waste in the system, and patients are under pressure to ensure that transplant is really what they want. Patients must commit to transplant and this causes a significant fear of failure, mainly surrounding fear of medication and potential failure in coping with the negative side effects of immunosuppressant drugs. Despite the potential for transplant to give patients another chance at life, many patients never become fully engaged in society. Thus, the notion that transplant will lead to socially and economically engaged citizens is perhaps flawed, particularly when patients have to wait so long on dialysis, which significantly impacts the severity of co-morbidities. As treatment options, dialysis and transplant are situated within a particular care environment that is orchestrated according to the organizing principles found in an opt-in organ donation system. Because of this, we find patients waiting for transplants that may never come. And this reality begs the question of whether such a system is the most effective, and what might patients seeking alternatives decide is a better choice for them. Thus, the following three subsections highlight types of organ transfer systems, beginning with patients' and medical professionals' perspectives of the current opt-in system, as well as their perspectives of alternatives to the current system that were identified in the literature review.

## **Organ Transfer Systems**

### ***Opt-in or Voluntary, Altruistic Donation***

The following subsection highlights the first of three transfer systems to be discussed, and patients' and medical professionals' perspectives in regards to its effectiveness and challenges. The range of knowledge participants had regarding the current system comprises the first component of this section. Next is a discussion of the reasons why the current system is considered effective or ineffective, first from patients' perspectives and then medical professionals'.

Patients demonstrated a range of knowledge about how organ donation and procurement works<sup>25</sup>. Those with little or no knowledge often became frustrated when asked to comment on the effectiveness of the current system. One patient stated the following, which demonstrates that a lack knowledge, particularly about wait lists, can be confusing and frustrating:

I think it's like the luck of the draw and if you've waited for this amount of time then maybe you'll get a kidney. And it's all about how healthy you are, how much you take care of yourself...they watch all of that and if you're a good patient and

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<sup>25</sup> Amount of knowledge was determined by patients' responses to probes such as *Do you know how the donation system works?* If respondents answered "no" or "not really" they were deemed as having low knowledge. Medium knowledge included responses where patients generally described the system but did not know the details, such as knowing the roles of different administrative bodies. High knowledge included respondents who had significant detailed knowledge of the organization of organ donation and procurement, of which many, though not all were medical professionals. Three out of six patients demonstrated low knowledge of the current donation system, two demonstrated medium knowledge and one demonstrated high knowledge. It is interesting to note that one of the medium knowledge patients and the high knowledge patient were the oldest of the patient respondents, perhaps indicating that with age, patients gain more knowledge of the system. Of the medical professionals, four demonstrated high knowledge while two demonstrated medium knowledge. It is interesting to note that the medical professionals with medium knowledge were structurally closer to the patients, i.e. nurses who worked daily in the dialysis clinic directly with patients. Their level of knowledge may be a reflection of the irrelevance of larger administrative issues to their day-to-day routine.

they like you, then you get it. I think that's how it really works. I don't believe there is a list. (Pat. 4)

Still, despite having varying knowledge, patients tended to hold unfavourable views of the current system. While they thought that the system works, such that they recalled having friends in the clinic who received transplants, they felt that too many people are waiting too long. The current system was thought to be ineffective because of organ shortages and the inability of organizations to capture willing organ donors. As one patient put it, “not enough people are signing their donor cards” (Pat. 6)<sup>26</sup>. This was thought to be the result of cultural or religious beliefs, immigrant status, lack of awareness, lack of education, fear, a desire to avoid negative thinking, increasing demand, the pace of life and associated apathy, and youth not wanting to think of themselves as vulnerable. Still, patients stated that the most significant factor impacting people's willingness to “sign their donor card” was that they simply were not aware of and did not care about the problem. Arguably, the characteristics of the general public that patients identify are social in nature, that is, they relate to daily activities of individuals within society including their culture, religion, country of origin, and lifestyle. These “social characteristics” were mentioned by patients as the dominant factors at play in the low number of organ donors. Patients felt that people only become aware of organ failure and the need for a transplant once it “touches” their lives. This idea that transplant has to

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<sup>26</sup> In the past, donor cards were distributed by the provincial government and people were urged to sign them and keep them in their wallet as an indicator of their willingness to donate should they get into a car accident or a similar situation. Now, consent is captured when people update their driver's licence or health card. People can also register online. The terminology of “signing your donor card” relates to the old system for registering consent and, although it may be the default terminology for registering consent, patients' use of this phrase may point to a lack of knowledge about how the government goes about obtaining transplantable organs.

“touch you” meant a great deal to patients. For example, one patient explained, “I believe it has to touch you for you to get it...you know about dialysis, you know about kidneys but once you’ve lived it and seen what people go through, you wanna give your organs up” (Pat. 6). Indeed, many patients recognized that before they needed a kidney, they themselves were not registered organ donors. For example, one patient explained:

When I was younger, I just thought, ‘when I die I just want all my parts, I wanna be buried and that’s it’. If you’re young and you’re healthy and you’re living life and you don’t really know anybody that’s sick...they don’t think it’s gonna really affect them so they’re not going to think about it, I know I did not think about it.  
(Pat. 4)<sup>27</sup>

In fact, four of the six patients interviewed actually stated that the only reason that they were aware of or cared about organ donation was that they were ill. For example, as one patient put it, “I’m looking at it from the other side, right? If I didn’t have kidney failure, I don’t know how I would feel about it, but because I have kidney failure, I think that everybody should donate” (Pat. 2). Patients thought that the best way to get people to register to be donors is through utilizing the concept of “touch”. Many believed that the most impactful strategies for the current system would involve telling stories about “what it’s like” to need a transplant, through advertising on television and education in the classroom. Still, others were not sure that anything could be done as the various social factors impacting decisions outweighed the efforts of organizations like Trillium. For example, one patient stated “I think a lot of people are quite selfish and could care less.

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<sup>27</sup> It is important to note that Pat. 4 and Pat. 5 were the only two patients out of the six who could have donated a kidney at some point in their lives, as the others had lifelong afflictions that would likely have led to their kidneys not being used. However, some of them may have been eligible for donating other organs upon their death, but none of the patients stated that they were registered organ donors prior to or after experiencing end stage renal disease.

You know? It's not happening to them, it's not happening to their children so, why bother? Why worry about it? That's somebody else" (Pat. 3). And when asked whether he thought articles published in newspapers had an impact on awareness, Pat. 3 argued

I think spur of the moment it does...you read the article and say 'gees that's terrible, maybe I should try and do something about it' and then you go on, the kids come in and they wanna go out and play hockey and it just disappears.

It appeared from patients' experiences that a lack of awareness is commonplace and until the issues "touch" you, you remain unaware, and perhaps uncaring. Overall, patients felt that the system worked, at least in that they were able to recall instances where patients received a transplant. Still, some felt that more could be done in terms of building awareness, while others felt that even more campaigning would not significantly increase the number of available organs.

As mentioned earlier, medical professionals provide a very different perspective of the current organ transfer system, methods of organ procurement and reasons why systems appear to be ineffective. This perspective tends to be related to administrative inefficiencies rather than to the more social characteristics that patients discussed. Unlike patients, medical professionals were generally in favour of donation as "the best strategy we have" (Prof. 6); however, they felt that the process of obtaining organs and getting them to recipients is so complicated and so political that "bottlenecks" cause the system to become ineffective. They explained the various ways that processes can be interrupted which include: intensive care unit doctors not being educated about the potential for organ donation and their unwillingness to follow through on procedures; the absence of donor

coordinators in many hospitals where donors could be obtained<sup>28</sup>; the disincentive for surgeons to book operating room time for organ removal or replacement due to its relatively low pay compared to other surgical procedures; the disincentive for physicians to get involved in nephrology specifically (the diagnosis and treatment of kidney disease) as it is not the most lucrative field of practice; governments not making well-enough informed decisions when it comes to providing funding for certain aspects of treatment and not others; and the slow progression of change as a result of constant measurement. Medical professionals tended, therefore, to focus on administrative inefficiencies rather than social characteristics, or blaming people for not being aware of the issues.

It was also common for medical professionals to point out that even with public education and awareness it is unlikely that the number of organs obtained from deceased donors will ever be enough. This idea of demand inevitably surpassing supply was the driver for medical professionals to talk about the strategies that have been employed to expand the donor pool, particularly in Ontario. These included the use of donors following cardiac death (DCD), in which Canada is currently a world leader, as well as gains that have been made with live donation and “extended criteria” or “marginal” donors. In terms of live donation, the system actually appears to be utilizing the power of “touch” as a motivator for friends and family to step forward to donate a live kidney. Extended criteria donors include individuals who, in the past, would not have been considered donors, such as the elderly, people with diabetes or hypertension or even infectious diseases, such as hepatitis. Extended criteria donors have expanded the donor pool particularly by providing transplant opportunities for people who find themselves in

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<sup>28</sup> Donor coordinators are trained and hired by Trillium to talk to families and obtain consent for removing their loved ones’ organs.

similar “marginal” health situations who, in the past, would not have received an organ. For example, a 20 year old kidney would typically not be donated to a 65 year old person with kidney failure; attempts are made to ensure the closest age match possible in this case. Today, rather than not receive a kidney at all, a 65 year old person can receive a kidney from a donor over the age of 60. Still, medical professionals recognize that although gains may be made in some areas, there is still a lot to be done. For example, Prof. 2 explained:

You always have to re-examine what you’re doing...Trillium does sustained reviews of ‘tier one’ hospitals - hospitals that have trauma or neurosurgical capacity, that’s where about 90% of the donors comes from...So there’s certain laws in place, but Trillium needs to maybe do that with more hospitals, cause there are probably donors that are being missed right now... [But] it’s too easy not to do this so you need a lot of resources [and] it’s far from perfect...we know we can do better.

Overall, medical professionals recognize that there are many issues at play when it comes to evaluating the effectiveness of a system. Patients wait an average of four years for a new kidney, and this will likely continue into the foreseeable future. Although there is significant pressure to transplant because it is cheaper than keeping patients on dialysis, improving on the existing strategies, such as keeping patients off dialysis through early detection or continuing to expand the eligibility requirements of both donors and recipients, is necessary. However, these improvements take time and resources, and change is slow. One medical professional expressed why he believed the process is slow from a broader societal level:

People are probably overly cautious and we really suffer as a society. Canadians are very safe and very slow and very insular. Most people just either want to go to the cottage, or have their Tim Hortons, they don't want to necessarily have the fastest transplant system in the world. They don't. They want to go home at 4. They want to snowmobile all winter. (Prof. 1)

It is therefore clear that social factors as well as administrative challenges impact the effectiveness of the current organ transfer system in Canada. While improvements are being made, change takes time, which means that demand will likely always surpass supply.

To summarize, among patients and medical professionals, participants demonstrated a range of knowledge about organ donation and the transfer system generally. This was likely the result of having very different experiences, which was reflected in the way that participants talked about the current system and how they judged its effectiveness. Patients generally felt that the system worked but organ shortages were persistent, as evidenced by long wait times, because people are not aware of what it is like to wait. They discussed a number of social characteristics such as culture, religion and fear that they felt motivated people to not register their consent to donate upon brain or cardiac death. Medical professionals, on the other hand, tended to cite administrative issues for why the system is at times regarded as ineffective. They were less likely to identify social characteristics; however, they did note the important role of Trillium in gaining acceptance and building positive attitudes towards donation among the medical community. We can see that from the patients' perspectives, the donation aspect of the system is only as good as the level of public awareness that is achieved, whereas medical

professionals believe improvements in administration ought to be the focus of the agencies and organizations involved.

### ***Opt-out or Presumed Consent***

Similar to the knowledge participants demonstrated in regards to the current transfer system in Canada, and in Ontario more specifically, knowledge about alternative systems also varied by participant<sup>29</sup>. Transfer systems that employ the opt-out strategy, or presumed consent, are the second of three systems discussed in this chapter because they were the most common alternative that participants brought up during their evaluation of the current system. This may point to the fact that opt-out is relatively well known. The perspectives of patients and medical professionals are presented below in regards to not only the perceived effectiveness or ineffectiveness of opt-out as a procurement strategy, but also in terms of its potential for increasing the number of available organs in Canada.

First, patients were highly favourable of an opt-out donation system and felt that it would be much more effective than the current opt-in system. The most significant argument for adopting such a system was that it would force people to become aware of the need for organ donation, which was explained by Pat. 2 when he said:

I think it would force people to be more conscientious of how much is needed - you pay more attention to it... 'Cause right now if you don't sign the card, who cares. Right? Whereas if people have to sign the card to say 'no,' they have to want to know more about it so that they know what they're signing.

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<sup>29</sup> Similar to the previous point on the knowledge of medical professionals, the closer a professional got to the patient structurally (i.e. nurses work more closely with patients than doctors), the less knowledge they had.

Similar sentiments were discussed by some of the medical professionals who stated that an opt-out system forces people to take a position on organ donation who perhaps at the moment do not think or care about it. Further, such a system was thought to allow for organs to be removed from people who currently do not take the time or spare the thought of opting-in. For example, Prof. 5 said “I think that’s brilliant because if you really felt strongly, you’ll write the letter [declining to participate]... [and] most people aren’t going to write that letter.” Some patients saw the potential of presumed consent as being an incentive to care as it presents a kind of “consequence” for not caring. For example, Pat. 1 explained “there’s no consequence, [if] that’s the right word? I don’t need to learn anything about this because this card right now means nothing.” Thus, there was significant support among patients and among many of the medical professionals for an opt-out system as it presents an opportunity to increase awareness as well as the number of available organs. Presently, people must step forward to donate, but, arguably, if they are not aware of the issue or are unaware of how to step forward, they are less likely to do so. Most believed that the public would be compelled to address donation, particularly if they felt it was something they did not want to do, and, most, especially patients, were highly favourable of a presumed consent system.

A few patients and medical professionals felt that if presumed consent was to become the law, it would help to make some of the administrative bottlenecks of our opt-in system disappear. For example, one medical professional felt that it would relieve the burden of physicians having to talk to families about organ donation. Instead, physicians could simply state, “Look, I am obliged by law to approach you” (Prof. 3), and this would be especially true in places without donor coordinators, such that an arrangement where it

is assumed that everyone donates “increases accessibility to have that conversation” (Prof. 3). Additionally, one patient described a shift in the perception of donation that may occur among the donor families, such that:

If a young person was in a car accident, the doctor wouldn't have to ask the parents to donate, he might go to them and say ‘The system in Ontario is that we will take his organs unless you say no’ and I think that statement would – if it was accepted protocol in the province – [lead] more parents or next of kin to say ‘Well, OK’ ...maybe they would rather that doctors ask them for the organs rather than beg. (Pat. 5)

Shifting the perception of donation through legislation recognizes that being given the choice to donate a loved one's organs occurs during an extremely difficult time. The distress families feel over losing a loved one may make the choice more difficult to make, and may lead some families to say no<sup>30</sup>. To remove the choice, then, may make the situation easier and lead to more donations. Overall, it was felt that changing the law and policies for implementing presumed consent or opt-out procedures in organ transfer would change the public's perspective about donation, and especially change the ways in which professionals interact with donor families.

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<sup>30</sup> There has been a great deal of discussion in the literature about the role of what is called “family veto power,” that families are given the last word on whether a loved one's organs are donated, regardless of the individual's wishes. It is argued that this leads to a significant number of families declining donation because in the midst of their devastation, families simply say “No.” However, in my research and through discussions with people in various professional roles across the organ transfer system in Ontario, this is not a significant problem, particularly in centres where donor coordinators are present. Loss of potential donors due to family veto may occur in the more remote or non-“tier one” hospitals, where donor coordinators may not have full time positions; however, there is little evidence to support the claim that family veto poses a significant barrier to procuring organs.

Other medical professionals tended to see opt-out strategies as no different from opt-in and, therefore, argued that implementing such a system would not be any more effective. It was pointed out that donor coordinators and intensive care doctors would still need to approach families to get their consent. This is because, as mentioned earlier, opt-out or presumed consent does not mean without consent. Because the current system insists on obtaining consent either from the individual or the donor family, if the system were to change to opt-out, families would still need to be approached and would still be given the right to refuse. Thus, some medical professionals felt that there would not be a significant change in perceptions of donation; the system would be very similar to what happens now. They argued that donor coordinators are highly successful in procuring organs in the current system and, therefore, perhaps we should be employing more donor coordinators. However, it was also recognized that for people who do not have family or available next of kin, their organs would be procured without consent. Still, medical professionals were not sure this would significantly increase the number of available organs. For example, Prof. 2 stated:

I don't think it makes much difference because in the end, [hospital staff] have to contact someone and make sure that that person – who has the close relationship with the person who's dying – goes through some reflection. It's only that portion of people that wouldn't have that relationship where that would be important in terms of numbers.

It appears that medical professionals do not all agree that an opt-out strategy would be more effective than the current system. This, of course, echoes the bigger debate that

continues among countries struggling to provide adequate organ supply that do not have presumed consent or opt-out systems.

Most importantly, and in spite of the overall positive attitudes participants had towards opt-out, none believed it would ever actually be adopted in Canada. There were many reasons given for why this is the case: patients mentioned that you cannot force people to do something they do not want to do, that people want to have control over their own body, that it would be a perceived violation of rights and freedoms, and that there would be too much push-back from people with specific religious beliefs. Arguably, these reasons reflect particular social values and patients understood that such a system would likely never be allowed to exist. The perceived violation of rights and freedom to have control and choice over what one does with one's body is likely a powerful driver for the form that organ transfer systems take. For example, Pat. 4 said "They don't wanna be controlled in any way...I think Canadians are more free-willed...if they're gonna be kind, they'll do it from not being told what to do". Similarly, Prof. 2 stated:

I think we live in a society where there's too much freedom of choice, in some other countries people may think that the state comes first, in Canada the individual freedoms I think play more of an important part of our value system.

Medical professionals provided still more reasons, including the fear that people have about being taken off life-support too early in the interest of removing organs, that law makers will never adopt a change so long as the public remains unaware and unconcerned about donation, that it would undermine the work that so many people have done up until this point, and that it would simply cause too much political turmoil as people are generally divided and, therefore, it would be a waste of time to try. And in fact, one

patient also noted “it could be an election issue of some amount that a government could get defeated over” (Pat. 5). Similar to topics covered in earlier sections, there is clearly a difference in what patients and medical professionals deem to be “deal breakers” when it comes to changing the current opt-in system to an opt-out system. Overall, there appear to be more social factors than administrative factors that would stifle the process of change. Interestingly, both social and administrative factors appear to come together when participants reflected on the political landscape and why an opt-out system would never be brought forward.

In summary, patients were highly favourable of an opt-out system and felt that adopting such a system forces the public to become aware of the issues of transplant and donation. It was thought that opt-out would increase the number of available organs, and some pointed to the impact that laws would have by making conversations with donor families easier for physicians. Still, some medical professionals felt that with an opt-out in system in Canada, family consent would still be required for obtaining organs from deceased donors and, thus, the system would not be very different than it is presently. Despite the support that so many have shown for opt-out, all participants mentioned that, ultimately, the political landscape in Canada would not support such a shift.

### ***Incentivized Donation***

The previous two subsections highlighted participants’ perspectives regarding the current opt-in transfer system, and the effectiveness and potential of opt-out or presumed consent systems. Assuming, based on the analysis, that presumed consent is seen as a more heavy-handed strategy that may even be in violation of people’s rights and

freedoms, it seems appropriate to raise the possibility of another alternative that is based on a more liberal ideology. Incentivized donation systems, and more specifically what patients and medical professionals think about incentives for organ donors, is presented in the following section. In particular, the section covers perspectives in regards to non-monetary (or hidden) incentives, such as governments providing tax breaks, direct monetary incentives, such as governments paying cash, markets and current practices that discourage incentives in the system.

It should be noted that, based on the literature reviewed in Chapter 2 regarding incentivized donation, participants were prompted to discuss both non-monetary (or hidden) incentives as well as direct monetary incentives, and whether they believed each would be beneficial and effective in Canada. In terms of the latter, some participants used the word “market” to refer to practices that either did or did not involve governments acting as regulators and buyers. In order to make distinctions between the different forms of “incentives” covered here, the term “monetary incentive” will be used to refer to government regulated transfer, with the government as buyer, while “market” will be used to refer to the free exchange between individuals that would be supported by the medical system, which would provide the requisite screening services and follow-up care. There is one additional relationship in organs transfer that is worth noting and which patients and medical professionals mentioned, that is incentives provided to living donors by recipients and their families, such as offering to pay for a vacation, a new car or mortgage payment. This form of incentive will only be discussed briefly as it is not easily substantiated given the scope of the data available for this analysis.

Generally speaking, neither patients nor medical professionals felt that non-monetary (or hidden) incentives would incite people to donate, particularly in the case of deceased donor families. However, there was some recognition that if hospitals (and by extension, the government) offered to cover the cost of funeral expenses, it may entice those without the financial ability to afford a funeral to donate their loved ones' organs. For example, Prof. 5 stated, "maybe a family who don't have a lot of money and didn't really think they wanted to donate, if you could help them pay for the funeral, maybe it would [lead them to donate]." Still, others felt that offering such incentives or other forms of reward, such as a plaque or a name on a memorial statue, would likely not convince people to donate who have already decided not to. Furthermore, such forms of incentives may bring in an element of coercion that would be viewed as distasteful. Prof. 4 expressed her apprehension toward non-monetary incentives as follows, "Maybe we make a donation in that person's name for something...I don't know...is that really going to help at the time? Or is that going to be a coercive message when you are asking for consent to proceed with donation?" It is important to note that for the majority of participants, non-monetary incentives were discussed in terms of a family's decision to donate a deceased loved one's organs, rather than incentivizing donor registration or live donation. Still, among those who discussed incentivizing live donation, it was felt that there would still be no increase in donation rates<sup>31</sup>. Prof. 6 explained that this was because she believes people are generally altruistic:

If people wanna donate, they're not doing it for a financial reason; they're doing it for a psychological reason. If they don't wanna donate, money is not gonna

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<sup>31</sup> Non-monetary incentives for donor registration or living donation were not discussed with all participants as it was later in the research process that probes were changed in order to address the distinction.

change that...there will be some who are swayed by it but for the most part, if people are going to donate, then they're gonna donate.

Thus, participants were not convinced that such incentives would make a significant difference in donation as those who want to donate will, and those who do not will not regardless of an offer to cover costs or provide tax breaks.

Based on participants' perspectives, non-monetary (hidden) incentives would likely not increase donation from deceased or living donors; however, there is significant support for direct monetary incentives presented in the literature review. Direct monetary incentives are commonly supported by members of the medical community (professionals) who claim that such incentives would at least increase donation from living donors who would receive payment. Interestingly, patients recognized that our system already compensates people for the cost of donating, such as for transportation and loss of income, and therefore in a sense, "we are kind of already doing that" (Pat. 5). While compensating for costs incurred is arguably different than paying above and beyond costs, many participants did not make that distinction. One medical professional, a physician, in particular was highly supportive of incentivized live donation, and he explained that the system could be organized as follows:

[It] would be regulated by the Ministry of Health in Ontario – it wouldn't be a contract between two people... donors would come forward to a hospital, they would be evaluated, we would give them some compensation for coming forward, [and] if they become organ donors, we would give them a higher level of compensation... [A] donated organ would go to the next person who needs it on

the list. And [the donor] would have great medical care, just like all our other living donors and the risk would be low 'cause they would be screened. (Prof. 2)

Thus, for supporters, a major strength of this form of organ transfer is found in there being a government regulated system, which would be safe and help to avoid black markets in organs. Also, the donated organ would be free to the recipient as it would be funded through taxes, similar to other medical services. It is interesting to consider the use of the word “compensation” to describe direct monetary incentives by the medical professional above. The word “compensation” is currently used to define the acceptable losses that a living donor incurs as a result of their donation, such as the cost of time off from work or the cost of transportation to and from the clinic. Though, “compensation” is synonymous with “payment”, the intention of the government is to make the process of live donation easier on the donor, such that it does not significantly disrupt other aspects of their lives. In the case of a monetary incentive system, however, the loss to a “donor” is an organ that would not have fetched income in any other circumstance, that is, the donor is making a profit. Compensation and payment then come to take on very different meanings in relation to exchanges for organs. By using the term “compensation” to talk about payment beyond costs incurred, individuals may be attempting to soften the intention of the practice. Based on this use of language, it appears that there may be some contention as to whether it is “good” to include monetary incentives in organ transfer.

Participants were asked to comment on what they thought of providing monetary incentives to live donors, which presented a significant challenge for them. Participants were often unable to express themselves or to communicate clear positive or negative opinions on the matter. As a result, interpreting their responses proved challenging. Some

medical professionals were able to point out some additional benefits of this strategy, such as more control for over matching donors to recipients and shorter wait times. And according to the physician who provided the example of this system, the reason why such a system would work is that:

Money is a motivator and that's OK...People sell their bodies for money...You can argue that selling sex does not really make you give up a body part but they're selling their bodies for money legally...If you are on welfare, and you can get 50,000 or 75,000 dollars, that could be a lot of money. Now maybe they won't make the best use of it, or maybe that's enough to get them a better apartment or put their kid through university... I know realistically there would only be a segment of the population that would do that, but, we haven't fixed poverty. (Prof. 2)

Like supporters in the medical community, patients also saw the benefit of such a system; however, there was an undercurrent of apprehension as to whether it would be "good" for people. For example, Pat. 4 said "I get the kidney and Tom gets the money, you know? That's the benefit. We all benefit from it. But...I don't know if it's a good idea." Other patients mentioned that monetary incentives could work so long as the system is regulated, "if it was checked and balanced then maybe it would work" (Pat. 1).

Participants were, therefore, able to identify some of the benefits of a monetary incentive system, mostly relating to the enhanced control within the system, the benefit to donors who would likely be in need of money, and the potential increase in the supply of organs.

Despite the positive evaluations that some participants were able to give in regards to the practice of providing monetary incentives to donors, there were also negative

evaluations. One reason why this practice was considered to be problematic was that it could “turn off” altruists, such that money would become a disincentive to give.

Additionally, it was thought that the government would go bankrupt paying people for their organs. Finally, one medical professional felt that by accepting such a relationship between an organ seller and the government, the government may be perceived by the public as compromising its ethical commitment to human dignity. Donation through direct monetary reward was also thought to be exploitative of people in a particular economic situation where money acts as a coercive factor in “giving.” Pat. 3 explained:

You’re gonna have people who are absolutely desperate for money, they’ll do almost anything. So those people, we’ll always have a few of those that’ll you know, gladly give up an organ as long as they can keep living and get some money that they can either blow or pay off some debt or whatever. But I don’t think the concept in general – I don’t think it would work.

Similarly, one medical professional indicated that he has a significant fear of what would happen in the future if such practices were adopted:

Are we gonna become a society that’s actually that bad? ... You know, the whole idea, it’s just not right. [Donation] should be driven from your heart....you won’t get these wonderful people but you will get these people who say ‘you can have my son’s kidney but now it’s going to cost you a couple thousand bucks, I know he’s dying but I know you guys are paying.’ (Prof. 3)

Indeed, when asked whether they thought that incentivized donation was inevitable given the current forms of social and economic organization, participants responded that although it may be possible, ultimately, money as a motivator is wrong.

Similar sentiments were revealed when participants were asked to comment on the potential of allowing for a market for organs in Canada, which would be supported by the medical system, though exchange would be among individuals. This was vehemently rejected as a supply solution by all participants for a number of reasons, which were mainly focused around fairness and equity. Fairness and equity were discussed in relation to the current universality of Canada's health care system, for example, one medical professional explained:

I believe that [a market] sets up a system for some people [who] could get it...so I don't think that's very fair because we have a health system that provides for everyone. So I do think it sets up a system of inequity. (Prof. 4)

Patients shared in this evaluation, but tended to more directly relate the issues of fairness and equity to Canada, and Ontario more specifically. For example, Pat. 5 explained "Everybody's supposed to stand in line in Ontario, rich or poor. So I'm sure that every poor person would be somewhat upset if a rich person got a kidney ahead of [them] simply because he paid for it." Pat. 5 also mentioned that to him, "the fairness of the old Canadians who were born in this country" ensures that no one would ever vote for such a system. A few participants also identified the "political misfortune" that attempting to implement such a system would cause, and, therefore, it would never become the dominant form of organ transfer. Indeed, other patients identified that "the concept of voluntary donation is very well entrenched" (Pat. 3) and they spoke often of the tradition of organ donation being strong in Canada. Medical professionals also spoke of tradition, but tended to focus more on the impact that a market would have in terms of undermining the work that has already been done. One medical professional felt that it would never

happen simply because “it’s too nice a society” (Prof.5). Overall, there was a strong rejection of having markets for organs in Canada, where individuals exchange money for organs with the medical system providing support through screening and transplant services.

In line with this rejection of incentivized donation, the current system is geared towards discouraging exchange between donors and recipients. As mentioned earlier, the system provides compensation to live donors who may claim particular costs from the provincial government, such as lost income caused by time away from work. The present system is also heavily committed to maintaining the anonymity of donors and recipients. Anonymity is regarded as fundamentally important to the structure of a system that supports deceased altruistic donation as it protects the privacy of donors and their families, and removes the possibility of recipient-to-donor reciprocation of any kind. Recipients may send a letter thanking the donor family for their loved one's organ, but letters are anonymous and there is no further facilitation of contact made by the hospital or Trillium. Still, some believed that exchanges do happen and, indeed, this is realistically more common in regards to live donation. It is difficult to prove and to chastise the relationship that a living friend or family member has with the recipient, such that, if the recipient offers to “take care” of the donor, make their car or mortgage payments or send them on a trip, there is little that medical professionals and other administrators can do. As Prof. 2 explained:

We have a very extensive team of people who just look after the donors; nurses, social workers, occasionally psychiatrists, physicians, and surgeons separate from the recipients, so they [scrutinize] these recipient-donor pairs but none of these

people work for the CIA, or FBI, so I can't imagine that they're gonna pick up everybody... [For example] you wanna give me a kidney and that's great and I'm gonna say 'I'm gonna look after you afterwards' and that's all I have to say....It's a little bit different than a signed contract, it's all subtleties...there's all kinds of potential coercions that can happen and I think it's naïve to think they don't happen, I can't imagine, human nature being what it is.<sup>32</sup>

Overall, the sentiment among many medical professionals was that we ought to work with and optimize the current system first, before ever turning to this more controversial and potentially exploitative practice of creating markets in organs in Canada.

To summarize, both patients and medical professionals felt that non-monetary incentives would not significantly increase the number of available organs as those who want to donate will, regardless of whatever small reward is being offered. However, there was more support shown for monetary incentives, and an example was provided of what this type of system could look like. Patients and medical professionals could see the benefits of a government regulated system where donors are paid for giving a kidney; however, there were also significant negative evaluations provided. This points to the fact that money as a motivator is seen as wrong when it comes to procuring organs in Canada. In terms of open exchange for organs or “markets” in Canada, both medical professionals and patients were fundamentally against their implementation as markets were regarded as unfair, potentially unsafe and ultimately in opposition to the fundamental values of

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<sup>32</sup> This final comment on human nature in relation to reciprocation for a kidney could relate either to the desire of the recipient to reciprocate as a social contract, which would mirror Mauss' conceptualization of the role of gift giving in societies such that recipients of gifts feel a responsibility to give back, or it could relate to the act of the donor requesting reciprocation from the recipient, which would show that donors view their own bodies as sites of income generation of some form. I believe this respondent meant the former; however, this distinction was not clear and could warrant further investigation.

health care. Finally, the current system discourages exchange through the maintenance of anonymity when it comes to deceased donors and through the use of screening when it comes to live donors. Still, some believe that exchanges do happen and they are perhaps less obvious than simply exchanging a kidney for cash.

It is clear that patients and medical professionals are supportive of both opt-in and opt-out systems, but identified significant negative aspects of systems that are based on linking organs to money in any way. Given that the last section highlighted an arguably more liberal approach to organ transfer, and left off with a discussion of markets in Canada, the next section takes this a step further to identify perspectives on markets outside of Canada, more specifically the international organs trade. The next section, therefore, highlights one final procurement option that patients may choose which involves the purchasing of organs from sellers in other countries.

### **International Organs Trade**

The international organs trade may not technically be considered a form of transfer system, as nowhere does it exist as such<sup>33</sup>; however, it involves exchanges between individuals that go beyond Canadians borders, and is a procurement option. This section covers perspectives on a range of topics relating to the international organs trade. The perspectives of patients are discussed in relation to the desire to participate and concerns regarding participation as well as other important considerations. Next, the perspectives of medical professionals are presented in regards to their concerns as well as the various challenges they face when attempting to address their patients' desires to

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<sup>33</sup> Though in some countries, such as China, there is evidence that suggests a formal administration exists for the purchasing of organs from prisoners by foreign buyers.

purchase kidneys abroad. A final discussion captures both patients and medical professionals' perspectives on the practice of purchasing non-transplant related medical services in another country. This final discussion is provided in order to demonstrate the ways in which patients and medical professionals perceive the act of purchasing body parts versus "normal" medical procedures, mainly as very different commodities.

All participants involved in this study were aware of the international trade in human organs. Patients and medical professionals alike demonstrated their knowledge of organs trade through telling stories they had heard while in the clinic, or stories related to their direct experiences, respectively. There were two stories in particular that were recounted in varying details. Both involved middle-aged men, with families, who had travelled to other countries and purchased kidneys. One man had a successful transplant while the other arrived back in Canada deceased having suffered a massive infection. The story of the latter was mentioned most frequently. When asked where they had heard about the trade, most patients stated that it was through the nursing staff and through popular media, such as television and movies. Similar to other types of knowledge discussed, medical professionals tended to have more detailed knowledge of the trade, the steps involved, locations where such transplant are carried out, etc., the further away they were from the patient structurally, such that physicians tended to have higher levels of knowledge while nurses tended to have lower levels of knowledge. Overall, it was clear that all participants were aware of the trade in human organs, and most told stories to demonstrate their level of awareness.

It is interesting to note that among the small sample of patients providing responses for this study, a trend emerged in terms of their perceived desire and

willingness to participate in organs trade. It appears that if one cannot afford to participate, there is a stronger desire to participate than if one can afford to participate. Of the three patients who could not afford to participate, two said that they would, and one said that it probably was not worth the risk. Of the three patients who could afford to participate, all said they would not, for various reasons which will be discussed in the next paragraph. This may point to a tendency of those who can participate to spend more time considering the logistics and issues of participation. Furthermore, they may tend to think about participation more because it is a viable option. For example, Pat. 5 discussed how his son had offered to pay for his travel to India, and while this would not be difficult for the son to afford, and despite the fact that the patient had no trouble accepting the money, he declined because he was concerned about the cleanliness of the facilities. On the other hand, perhaps those who do not have the financial ability to participate have not seriously considered participation as a viable option and, because of this, may tend to only see the benefit. Interestingly, the finding that patients who can afford to travel abroad choose not to is contradictory to what one might expect to find. Arguably, if one has the financial ability, then it becomes possible to go abroad, to be transplanted sooner, and to get off dialysis as opposed to waiting and suffering. However, this was not the case. Those who could afford to go likely put considerably more time and energy into thinking about participation and weighing the pros and cons. As mentioned earlier, an analysis of desire to participate was a particularly important component of this study. Desire, then, appears to be to some extent dependent upon whether or not a patient can afford to travel abroad to purchase a kidney.

Those willing to participate provided conditions they felt must be met in order to go through with purchasing a kidney abroad. Interestingly, the conditions of participation for these patients were mirrored in the concerns that all other patients expressed and tended to centre on a concern for personal safety. More specifically, the conditions of participation for those willing to participate in the trade were: having the financial ability, a guarantee of quality and safety, and being able to trust the doctors and other medical professionals involved in the transplant. They also demonstrated a preference for transplants in relatively affluent Western countries such as Australia. Indeed, when asked if and why she would seriously consider going abroad to participate, Pat. 6 stated:

If I had the money and if I could be guaranteed, sure, why not? I mean you're taking a risk either way...if I got [my husband's] kidney or somebody's kidney, who's to say my body wouldn't reject it? So, if I had the money I would – if I could be guaranteed it was good and not gonna hurt me or anything.

Similarly, those unwilling to participate identified reasons for their choice that included: the danger associated with a lack of cleanliness, the impossibility of a guarantee of safety and quality, the inability to establish trust as the care team is “just a guy's name on a piece of paper” (Pat. 3), the complicatedness of planning and travel, the discomfort that would be experienced while travelling, and the risk of death and concern about their families' wellbeing. In addition, the two older patients expressed a strong commitment to the system in Ontario and to Canadian health care generally. For example, Pat. 5 explained:

I like our system, we're dealing with Ontario as opposed to some other country like China or India or the Philippines...I just don't think I would go that route. I

would want to deal with Ontario because I think our system is superior, I think our abilities are superior. You know when I get on the table I don't really wanna die on the table. At my age, I think I need a good surgeon to look after me so I wouldn't consider going to another country.<sup>34</sup>

All patients are fundamentally concerned with their own personal safety and a guarantee of quality when it comes to their care and the kidney they would receive. However, those who are unable to participate are arguably less specific about their concerns when compared to those who are able to participate. For those able to participate, the reasons why they do not are associated with issues like planning and travel, and why they feel they could never really trust medical professionals abroad. As argued in the previous paragraph, this may be because those who are able to participate spend more time seriously considering purchasing a kidney abroad as an option, and this may be demonstrated in their more specific reasons for not doing so. Overall, personal safety was the most common concern for all patients whether they could afford to participate or not.

One other important factor in decision making that was identified earlier in this study is patients' concern about exploitation. It should be noted that exploitation is broadly defined as the utilization of impoverished populations, mainly their bodies, for fulfilling the need for organ transplants. Concern about exploitation as a factor influencing decisions to participate in organs trade was assessed on a range from high to low concern. High concern means that the participant mentioned exploitation as an important aspect of participation, without having to be prompted to talk about it (i.e. they were unprompted and concerned). Medium concern means that the participant did not

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<sup>34</sup> When looking at these responses in the broader context of the entire interview, it appeared that for older patient, their strong commitment was partially tied to the fact that they felt they had paid into the system for so many years and were now using what they have paid for.

discuss exploitation until they were prompted, at which time they talked about their concerns or what they knew about exploitation in organs markets, (i.e. they were prompted and concerned). And finally, low concern means that the participant did not mention exploitation until prompted, and, at that point, it was not discussed nor regarded as important (i.e. they were prompted and not concerned). It should be noted that all participants were given examples to demonstrate what exploitation is in terms of this study. For example, participants were told of a poor man living in a slum in India who has no work and so much debt that he sells his kidney to make ends meet, only within a year, the man is back where he started. Participants would then be asked to reflect on their concern about exploitation. Looking at the range of concern about exploitation, only one patient was highly concerned. This patient also did not desire, nor was he willing, to participate in organ trade. All remaining patients, including those who had stated they would not purchase a kidney abroad, had low concern, which appeared to be due to their need and desperation outweighing their concern for others. For example, Pat. 4 explained “I’d be concerned but once again, I need it. You know? I’d be concerned but not really, like it wouldn’t – it wouldn’t be the determining factor of what I’m gonna do”. When asked whether they were concerned about the exploitation of poor people involved in organs trade, a majority of participants said that they were not concerned. Furthermore, when asked whether exploitation would be a significant factor in their decision to participate or not participate, the majority of patients responded that it would not.

Although patients were not concerned about the exploitation of poor sellers as vessels of “spare parts,” some were concerned about the use and misuse of their money after a kidney was purchased. For example, Pat. 4 explained:

I'm not a gambler, so I would definitely be concerned about who's really getting the money. I think about that even now when I see those commercials about kids from Africa and the donations...I'm one of those people who would think 'are they really getting this money?' So definitely, if someone came to me saying, you know 'is this person gonna get?' I'd definitely think. (Pat. 4)

A concern about how a payment for an organ gets divided up does not point to a concern about the exploitation of bodies. It does, however, point to a concern about the role of "middle men" in not giving a person what they are due, which certainly is a form of exploitation. Although such sentiments show a concern about one form of exploitation, they do not question nor do they challenge why sellers are in the position to sell in the first place. They do not challenge why some (poor) bodies are vessels of spare parts while other (rich) bodies are not. Pat. 3 also felt concerned about where his money was going but for a different reason, that it would be squandered. He stated:

Most people like that, they'll blow it and they'll be right back where they were before, or they'll go out and buy the Rolex watches and enjoy themselves...I think those kind of people just live from day-to-day and if they've got the money in their pocket they'll just blow it.

Here, sellers are blamed for their socio-economic position, such that they are, by virtue of their poverty, unable to realize the value of money. Perhaps these comments, concerns about distribution and use, illustrate a general understanding of organ sellers as rational actors involved in an economic exchange, rather than as victims themselves. Comments such as these does not demonstrate a concern about how sellers wind up in such a desperate situation, but rather, they demonstrate a concern about money, about its use and

misuse, such that sellers are rational economic actors that ought to be given their share and spend it wisely. At the same time, others expressed little or no concern about where their money was going. For example, when asked whether he had concerns, Pat. 2 stated “not really...’cause if I’m paying for something and I receive what I pay for...I mean I have no control over where my money goes when I buy something else, right? So, not really. No.” Thus, the level of concern that patients have about sellers and the use and misuse of money are mixed. While not receiving fair pay is potentially one form of exploitation of the poor, patients overall are not concerned about the exploitation of poor bodies as sites for organ harvesting. It appears that poor organ sellers also tend to be regarded as rational economic actors in an exchange. Furthermore, this tendency may mask the exploitative nature of the sale in the minds of patients.

Medical professionals had a greater range of concern about exploitation than patients. It should be noted that medical professionals were asked to discuss their own personal concern as well as their patients’. In terms of their own concern, those with high concern were more likely to use the language of “victims” when talking about those who turn to selling kidneys to generate income. Indeed, Prof. 6 said:

I’ve got a problem with it. Um, partially ‘cause you have no idea what the person went through who’s giving the kidney. Were they led to the slaughter house or were they paid anything for the kidney? Pennies? What kind of health did they have? I think it’s just, they’re victims and I think it’s really unfair to be offering the kind of money that is offered for organs.

One medical professional identified the broader socio-economic and structural issues involved in the creation of organs trade, and showed support for government intervention, particularly in developing countries. He stated:

It is a social issue cause why else would you, like I cannot imagine why somebody would be selling an organ otherwise. I mean, you're being pressured by something financially, which usually has to be quite devastating I would think, where the social system should come in, that's where government should come in and protect those individuals. (Prof. 3)

Thus, a couple of highly concerned medical professionals victimized organ sellers, recognizing the exploitation involved in the trade. Others, however, did not show the same degree of concern for organ sellers, and seemed less likely to victimize them. It is difficult to determine why this was the case; however, their concern tended to be centred on their patients, as opposed to the person selling. Interestingly, two of the medical professionals with low concern and no strong opinion towards the trade also supported incentivized donation, while the remaining two medical professionals stated that they were "on the fence" about their feelings towards organs trade. Those who were "on the fence" stated that purchasing a kidney is a choice for some people, that it fills a need, that it is like buying any other medical service abroad, that it is making a difference for some people and that it reduces wait times. However, while they acknowledged the potential benefits, they also acknowledged that it may be unethical to buy a kidney from someone who is experiencing coercion as a result of poverty, but little expansion was given on this point.

Ultimately, a majority of medical professionals and patients expressed that when it comes to others, that is, when it does not apply to them, they understand why people go abroad, and they understand why people turn to selling a kidney. They have mixed feelings about whether or not it is a morally “right” or “wrong” practice.

In terms of patients’ desire to participate, every medical professional identified desperation as the main reason why patients go abroad. Desperation for patients, according to medical professionals, takes on many forms including desperation to get off of dialysis, to get better, and to “live a normal life” (Prof. 5). For example, when asked the reasons why patients buy kidneys in other countries, Prof. 6 stated:

Absolutely hating dialysis, needle phobic...[if] they’ve never come to terms with the fact they have chronic illness, [if] they require dialysis till transplant and balk at it every time. We have a few of those. I mean they’re angry coming in three days a week and you think over time they’re going to get used to that but it’s just a wall. The patient in that condition who has no live donors and knows that this is what they’re facing for the next, at least six years, I can see them looking elsewhere.

Thus, it seems that from the medical professionals’ perspectives, patients who travel abroad cannot stand the negative aspects of dialysis and cannot endure them long enough to get a transplant through the donation system. Medical professionals mentioned that those who go abroad tend to be young (between 40 and 60 years of age) males with family that they support financially, who are in the prime of their career and do not have a living donor. Furthermore, they mentioned that among this group, a sudden decline in

quality of life, a need for control and foreign national and immigrant status<sup>35</sup> are all strong predictors of participation. Finally, medical professionals also mentioned that perceived pressures to maintain a particular lifestyle tend to exacerbate a patient's desire to get better quickly, in order to return to work. It was the contention of one nurse that if money were not an issue, most of the patients currently in chairs in her clinic would go abroad. She stated "I think you would do what you could do to make your life better. We only have so much time on this earth and I think if you can make it the best, most people would" (Pat. 5). Overall, medical professionals deemed desperation, which appears may be associated with a patient's stage of life, to be the driving factor in patients' decision to purchase kidneys abroad.

Medical professionals involved with dialysis and transplant understand that an important part of their work is mitigating patient expectations, as well as their desperation. As mentioned, home dialysis is one form of treatment that patients tend to view positively as they are often able to regain a sense of control over their lives. On top of such treatment strategies, medical professionals also take on the role of educator when approached by patients about purchasing kidneys abroad. Educating patients about the potential costs and benefits, about the "facts," of travelling abroad, seemed to be more common the further away the medical professional got from the patient, such that there is less "education" given by nurses and more given by physicians. Interestingly, not all physicians felt that this was a role they were comfortable taking, and some chose not to, as they tended to lean towards professional neutrality. Prof. 1 explained that he tries to

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<sup>35</sup> The statuses of foreign national and immigrant (mainly recent immigrant) are related to the practice of a current Canadian citizen, with family or friends residing in their country of origin, travelling "home" to receive a kidney. It is difficult and oftentimes impossible to determine whether the kidney donor is related to the recipient in any way, whether they are receiving payment for their donation or are experiencing other forms of coercion.

communicate that he “strongly recommend[s] against it,” but at the same time, he strives to make his patients feel like he trusts their decisions. As Prof. 2 put it “It’s hard to tell desperate people what to do and what not to do”. Indeed, it appeared that physicians, in particular, struggle with their desire to inform patients of potential risks, but at the same time maintain their professional neutrality so as to not seem patronizing. Still, for those who do provide some form of education, they tend to highlight the personal risks, such as death, “overwhelming sepsis” and “fungal pneumonias” (Prof. 3), and the chance that the drugs that will be provided abroad are merely placebos. Despite their personal or professional convictions, all medical professionals felt that if a patient were to come back with a new kidney, they would have to treat them. Although agreeing to treat patients returning from abroad is up to the individual physician<sup>36</sup>, patients are told that they will receive follow-up treatment when they return to Canada, but it may not be from their original physician. Thus, the role of medical professionals is extended beyond mitigating the expectations of their patients and includes mitigating their desperation as well. Mitigating desperation and patient interest in purchasing an organ abroad is achieved through implementing alternative methods, such as home dialysis, as well as through education. Yet, despite the impact that hearing the opinion of a physician may have on patients’ desire to travel abroad, many medical professionals, physicians especially, feel that it is not their place to help patients in making their decision.

Interestingly, it appears that patient education hardly ever involves a discussion of exploitation. Rather, it is typically centred on danger and risk. Indeed, even among those medical professionals who expressed a medium to high concern about exploitation, when

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<sup>36</sup> Though it is not something that is widely known or discussed, according to the medical professionals interviewed, it is not uncommon for physicians to refuse to treat patients returning from abroad with a purchased organ.

asked what information they provide to a patient considering participation, exploitation was rarely included. When asked why not, medical professionals explained that mentioning their personal concerns about exploitation was not their place, and might be seen as passing judgment. Prof 1 stated, “you can’t take care of these guys and get all finger waggy...they don’t have a lot of options...they trust me...if [trade] does come up as an issue, I tell them I don’t have an opinion.” This supports the notion that medical professionals feel that the decision to go abroad is the patient’s to make and, thus, it is not their place to be judge or to be “patriarchal”. Overall, only one medical professional explained what he would say to a patient who came to him thinking of buying a kidney, which included a concern about exploitation:

[I] kind of [try to] reinforce that idea... ‘you are encouraging that particular trade’ ...so it’s not really an element of guilt, I guess partly it is but it’s also an element of reality that you have to put in there and say, ‘hey, I just hope you know where you’re getting this kidney from’, whether you’ll feel comfortable living with yourself knowing that somebody had to sacrifice an organ so that you could get it [and] so that some other guy in the middle can make money...I think they often don’t think about that aspect...they actually haven’t thought about it that far away... it’s maybe cause they don’t want to know. (Prof. 3)

Given that only one medical professional felt compelled to remind patients of the potential exploitation of the market, it appears that medical professionals are not likely to discuss it. This appears to be due to a conflict resulting from their position of power and authority and feeling unsure about expressing their personal concerns.

Patients and medical professionals were also asked to discuss their perspective on an activity that is often related to organs trade, and that is the practice of medical tourism and purchasing medical services in other countries. Medical tourism involves travelling to another country in order to receive treatments that may not be offered at home, or that are offered in a more timely fashion, and often involve luxury vacation and hotel packages. When asked how they felt about medical tourism in countries such as the Philippines and Thailand, such as obtaining heart surgery, patients and medical professionals were supportive of such activities. Being able to afford and acquire needed treatments sooner was regarded as a positive aspect of health related travel. More specifically, a few patients expressed the sentiment that although it might not be fair, because only those who can afford to participate in medical tourism do, it is nevertheless necessary in some cases. From a medical professional's perspective, private overseas clinics were seen as providing much needed "frugal innovation" (Prof. 1), which amounts to developing innovative ways to provide services in low-cost conditions. They stated that countries like Canada can learn a great deal from the methods that are employed in other countries, particularly when clinics specialize in one type of treatment. What is more, because these clinics are based on a profit model, it was felt that they produce highly efficient and effective services. Interestingly, one medical professional pointed out that buying medical services abroad is not unfair only so long as the system in a person's home country maintains a high quality:

In a country like Canada where we do have a great baseline level of health care that's available to patients, if somebody goes abroad to get this treatment earlier because they're wealthier, then I think it's really their choice. It's like getting a

car, 'what car do I wanna get, do I wanna get a Toyota or do I wanna get a Mercedes' whatever you want, it's that choice. (Prof. 3)

Equating purchasing non-medical services with purchasing other consumption items such as cars reveals an important distinction between non-transplant and transplant services. For example, when asked whether he would consider buying a kidney, Pat. 2 felt that buying a kidney was not like buying "a bag of milk" or "a tank of gas." What this discussion may reveal, then, is that there is likely something fundamentally different about organs that leads people to have more negative attitudes towards organs trade than medical tourism. This may be due to the reality that in order to get a kidney, someone has to sacrifice, whereas no one has to sacrifice for someone to get a heart bypass. For example, Pat. 6 explained that in the case of non-transplant services, "nobody's gonna give up an organ, nobody has to give up their boobs to get a boob job [participant laughs] that way it's OK 'cause somebody's not sacrificing themselves." Thus, patients and medical professionals had positive attitudes towards purchasing medical services in foreign countries because they do not involve purchasing an organ that requires a far greater (human) sacrifice.

There is an additional point raised among medical professionals regarding the prevalence of foreign nationals and recent immigrants becoming organ buyers more so than second, third or fourth generation Canadians. Most medical professionals mentioned that individuals with either of these statuses who travel to their country of origin to purchase organs tend to have an understanding of the organization of organs trade and networks through which to carry out this activity. They stated that they also appear to be more likely to bring an organ donor to Canada to arrange a live kidney transfer. In this

case, medical professionals explained that they were weary of such arrangements as there is no way of knowing whether coercion is involved. The person who is brought to Canada for donation is screened much more thoroughly than a living donor currently living in Canada. As mentioned elsewhere, screening involves both a thorough evaluation of physical as well as psychological health, and donors are asked to explain why they are donating a kidney to the recipient. This heightened caution and screening process is due to the fact that foreign donors tend to be friends or distant relatives of the recipient, while living donation in Canada most often occurs between immediate family members. Based on the information given by medical professionals for this study, it is likely the case that a significant portion of cases where Canadians purchase organs abroad involve foreign nationals who opt to participate in the trade rather than wait for a donated kidney in Canada.

It is also important to consider the reasons why foreign nationals with a willing living donor in Canada opt to purchase a kidney abroad or opt to bring a living donor to Canada from their country of origin. This reality was problematic for one medical professional who stated that he feels a great deal of frustration when his patients choose to return to their country of origin to buy a kidney rather than choosing to receive a kidney from a willing immediate family member already living in Canada. When interviewing patients, it became clear that receiving a living kidney donation from a family member, especially from a son or daughter, is not easily accepted. Many patients who were parents expressed a concern about receiving an organ from their “child” (i.e. son or daughter of any age). They felt that by giving a kidney, their child’s life might be jeopardized; that they might be “less whole” after the procedure. Another patient explained her experience

of receiving a kidney from her sister who had post-operative health difficulties that concerned her greatly. Choosing to receive a kidney from a family member is difficult for patients to accept, particularly when they are concerned about the health and safety of the individual who is donating and may be one reason why foreign nationals opt to purchase organs abroad rather than receive one from an immediate family member living in Canada.

In summary, patients identified a number of concerns regarding participation in the international organs trade, which tended to be about personal safety. Furthermore, the potential risks to personal safety involved in participation outweighed the potential benefits, such as getting off of dialysis and returning to a normal life. Whether a patient has the financial ability to participate is relevant to their decision making; however, it was not in the direction that one might assume. Those who could afford to participate felt that purchasing a kidney was not a solution for them, as the risks outweighed the benefits. Overall, patients are not concerned about the exploitation of organ sellers abroad, which was also found among most of the medical professionals. Medical professionals tended to be more concerned about their patients than about organ sellers. This was partly due to the fact that they, particularly physicians, felt it was not their place to impart judgment, as they wished to retain their professional neutrality. Few felt comfortable providing information to patients about the exploitation associated with organs trade. Medical professionals identified desperation among a number of factors that push patients to travel abroad for kidneys; however, foreign national, immigrant status and a concern for familial wellbeing also appear to be likely determinants. Finally, all participants supported medical tourism as one way to fulfill the need of patients who can afford to participate in

such practices, and as a potential way to improve services at home by providing cost-efficient solutions.

## **Conclusion**

This chapter brings to light the lived experience of those who currently operate within the organ transfer system in Ontario, Canada. By contextualizing the lives of waiting patients and the work of medical professionals, we can form a better understanding of the opportunities and challenges that each of these groups face in carrying out the processes of treating end stage renal disease. We can also better understand the complex ways that participants evaluate organ transfer systems and their potential for improving the Canadian system. We also come to understand why patients choose to travel abroad, due their desperation to regain control over their lives. Patients have a choice: they can either stay to wait for a donated kidney, or they can travel abroad to purchase a kidney. It appears that the majority of patients, the ones interviewed included, choose to stay and wait. Based on the findings presented here, we can begin to unravel the reasons why this is the case. We can seek to find connections between patient decision making, their perspectives regarding exploitation and trade, and the values that are held to the highest esteem in Canadian society. Most importantly, within these findings it is possible to find an answer to the main theoretical question of this thesis. The next chapter will provide a discussion of the main findings presented here in terms of the values that are expressed through a discussion of organs transfer and trade.

## CHAPTER 5: Discussion

The previous chapter highlighted the perspectives of those involved in organ transfer regarding organ transfer and trade. Specifically these perspectives included those of hemodialysis patients in Ontario and medical professionals involved in their care, in order to determine where Canadians fall between the opposing value positions of consumerism and altruism. Patients make decisions regarding their care within a complex social, cultural, political and economic nexus. There are, therefore, a number of factors influencing their decision making when it comes to procuring a needed kidney. In order to determine how values influence patient decision making, and in what way, we can begin by proposing that the conditions that create organ buyers are present in Canada. However, the values that lead patients to choose the market are arguably different from those that lead patients to wait for voluntary kidney donor. Further, the organization of health care in Canada may lead to some confusion around when it is most appropriate to commodify the body and organs, and by whom. Based on the interview responses and the literature presented in Chapter 2, the following provides a discussion of the key findings, and is an attempt to answer the research questions presented in this study. This chapter has three sections. The first section discusses the experiences of patients and medical professionals in relation to the literature reviewed regarding the *Political Economy of Care* and how ideological shifts have led to transformations that impact the lives of the users and purveyors of the system. The second section, entitled *The Canadian Organ Buyer*, highlights how social, cultural and global ideological factors affect the position of relatively wealthy Canadian dialysis patients, and how their perspectives on organ trade and transfer appear to be influenced by them. Finally, *The Foreign Kidney* presents the

argument that based on the ideas expressed throughout this analysis, foreign organs are different from Canadian organs, a difference which creates the conditions for participating in organs trade. These sections, then, aim to provide an answer to the research questions under investigation.

### **Political Economy of Care**

As discussed in Chapter 2, particular ideologies are reflected in the organization of health care services. As a result of structural transformations, the ways in which patients and medical professionals experience the care environment and the ways in which patients make decisions regarding health have changed over time. Canada's liberal welfare state medical system is a mix of public and private interests, which influences the way in which patients and professionals experience the care environment. Competing interests in Canadian health care and their effects are well studied (e.g. Swartz, 1998). Armstrong and Armstrong (2003) note the structural changes that have been witnessed in the system as conservative ideologies came to dominate the political arena in the latter half of the 20<sup>th</sup> century. For example, cost reductions in the public system were achieved through the implementation of neo-liberal policies which included longer working hours and higher worker turnover (Armstrong & Armstrong 2003), as well as a shift in the production of care towards meeting "consumer" or "client" demands (Armstrong, 2003). Coburn (2006) asserts that this shift reflected the broader global spread of liberal capitalist ideologies where developed market economies sought to increase their global competitiveness through the liberalization of services. As a result, Canada's liberal welfare state health care system is merely a basic security model that essentially functions in the interest of capital and profit (Coburn, 2006). Although it continues to be funded

through a tax based insurance system, it is administered by private institutions. In the current model, the state is kept at arms length to the professional associations and administrative boards of care centres, and often private interests direct the flow of public and private funds into particular fields of care rather than others that are seen as less important (Friedson, 1970). Inefficiencies in the system tend to be downloaded onto both health care workers and patients (Curtin, 1999). Some argue that since the end of the 1970's, the organization of health care in Canada has changed and much of its original structure, which was based on accessibility and universalism, has been dismantled (Armstrong & Armstrong, 2003). Given the history and structure of health care in Canada, it is important to draw attention to the ways in which the liberalization of services affects patients and professionals within the care environment under investigation. The following three subsections, entitled *Self-Care and the Patient-Client*, *Accessing Needed Services*, and *Mitigating Desperation*, discuss instances where the structure of care impacts the experiences of both patients and medical professionals, in the context of kidney transplant services. These subsections, therefore, provide points of discussion that relate the literature presented here on the political economy of health and health care literature to the experiences of participants "on the ground."

### ***Self-Care and the Patient-Client***

The political economy of health considers how the organization and distribution of services ensure or threaten the health of a society, shape the ways in which individuals define health and illness and make explicit the extent to which individuals are accountable for their own health and illness (White, 2009). A liberal approach to care, first and

foremost, tends to base the provision of services on a consumer model, meaning that the system ought to provide patients, as rational economic actors, with choices regarding their care options (Armstrong et al., 1999). Medical professionals tend to view their patients as clients who are not only capable of making decisions about their health, but are also accountable for the outcome of their treatments. One example of how a liberal approach to care plays out in terms of patient relations can be seen in the preparation of patients for transplant. As mentioned, patients are prepared for transplant both physically as well as psychologically. They are told that they are responsible for whether their new kidney fails or succeeds, such that they must commit themselves to the required lifestyle changes and drug regimens that follow transplant. From the perspective of health care providers, this is important in order to reduce waste in the system, such that a graft failure means that an organ that may have been successful in someone else, perhaps someone more diligent in their self-care, has gone to waste. As a result of this pressure, patients come to question their ability to comply with post-operative regimens, and many fear that they will fail in this endeavour. Arguably, such an emphasis on self-care sets some patients up for failure, which would likely then be internalized as being their own fault. Thus, some patients become apprehensive given their newfound responsibility to care for themselves and their new kidney.

Yet another example can be seen in the relationships between medical professionals and patients in terms of information sharing. Based on the findings, it became clear that medical professionals strive to remove personal connections between themselves and their patients, often opting for professional neutrality. While they provide information to their patients in terms of their illness, treatment options, and what to

expect, they do so on the assumption that, ultimately, patients have to decide how best to manage their own care. Further, medical professionals generally felt that imparting what they consider to be personal opinion was paternalistic given their focus on meeting patient-client needs. The freedom to choose how treatment for end stage renal disease (ESRD) is managed could provide patients with a sense of control over the process; however, assuming that patients are capable of the level of self-awareness and self-care that medical professional expect, may not be appropriate. Ultimately, what these examples show is that patients are under pressure to become specialists in their own health, which may not be a reasonable expectation, yet is part of a client model of care (Armstrong et al., 1999).

### *Accessing Needed Services*

Access to needed services is an important component of any health care system, yet Canada's system struggles to provide adequate services in many areas of care, particularly kidney transplants, given the length of time patients can expect to wait. It was found that medical professionals identified a number of administrative inefficiencies and political "bottlenecks" in the current system that they felt reduce the number of available kidneys. These inefficiencies included a lack of education among intensive care unit doctors about organ donation and its processes; the unwillingness of doctors to follow through on the procedures of organ removal, whether based on personal, logistical or cost concerns; the absence of donor coordinators in many hospitals where donors could be obtained; the disincentive for surgeons to book operating room time for organ removal due to its relatively low pay compared to other surgical procedures; the disincentive for

physicians to get involved in nephrology specifically, as it is not the most lucrative field of practice; funders, including the government, not making well-enough informed decisions when it comes to providing funding for some treatments and technologies and not others; and the slow progression of change as a result of constant measurement. It was stated that all of these factors result in the lengthy wait times that patients on dialysis can expect before receiving a transplant. Importantly, the inefficiencies that medical professionals identified demonstrate a conflict in care. The system is compelled to provide patients with needed kidney transplants; however, it must do so in an environment where private profit, as well as careful cost containment, are of ultimate concern. Swartz argues that “the fragmentation inherent in a system characterized by individualism and competition defies service delivery” (p. 543). Arguably, the administrative challenges that exist in a system that is a mix of public and private interests affect service delivery as they prolong the suffering of patients on dialysis, and, what is more, likely lead to the increased desperation of patients over time.

The effects of liberalized care can also be examined in the context of medical tourism, in particular, travelling abroad for non-transplant medical services. As mentioned in Chapter 2, medicine in Canada is an industry, which impacts the ways in which people seek out and access medical services. As an industry, the system relies on private entities to provide the drugs and technologies that are utilized in and outside of the clinical environment. When the system cannot provide the healing commodities that are required to treat illnesses, patients understand that they may be required to seek out these components of care themselves and bear the upfront costs (Clarke, 2004). Thus, patients understand that care is also available in the private sector, if one can afford it. In the case

of medical tourism, all participants were in favour of travelling abroad to purchase medical services. Not only did they have positive evaluations of this practice, they felt that the choice to purchase medical services through private sector providers is a right for those who can afford to avoid the Canadian system. The practice of medical tourism was highly favoured among medical professionals as well, who also identified the benefits of having private clinics specializing in particular treatments. As mentioned, the for-profit model was seen as an important driver of frugal innovation (cost effectiveness and efficiency), which could then be shared in places where systems are not fully market-based, such as in Canada. Overall, there was a great deal of support for the commercialization of medical services outside of Canada, and patients and medical professionals felt that should one have the financial ability, avoiding the public system in Canada through participation in medical tourism can provide treatments faster, and perhaps even provide better, more effective services.

### *Mitigating Desperation*

One finding that was surprising given the focus of a great deal of work in the political economy of health and health care related to patients' evaluations of home dialysis. Taking a political economy of health and health care approach allows researchers to challenge the taken for granted activities that occur in relation to service provision. Part of this approach involves considering the impact that structural change has on individuals, families and communities. For example, Armstrong and Armstrong (2003) challenged the shift towards care in the home or community that has been occurring across Canada's health care system. They point out that shifting care into the home is designed to reduce

the costs within the system; however, the cost burden is downloaded onto families, and particularly women, who tend to be care providers in the community. As mentioned earlier, the costs of dialysis are many, and the burdens are significant for the health care system as well as for individuals and their families. While this study did not seek to highlight the impact of home dialysis on spouses, it is interesting to note that there appears to be a divergence from the literature in relation to the lived experience of patients doing home dialysis. Home dialysis has a number of benefits, the most important of which is its ability to mitigate the desperation patients on dialysis feel towards obtaining a transplant. For the health care system, the benefit of home dialysis is its ability to reduce costs of keeping patients in clinics which required a great deal of resources. However, home dialysis also appears to make waiting for a transplant more bearable for patients. This study revealed that patients overall had positive attitudes towards home dialysis for a number of reasons, including an enhanced sense of independence, freedom from the clinic and control over their illness. It was, however, noted that those without a spouse or other family member capable of helping with the dialysis process are generally unable to implement this form of treatment, and, therefore, are unable to reap the benefits that home dialysis can provide. Also, home dialysis can be potentially dangerous should something go wrong. Still, it seems that home dialysis is a potentially valuable strategy for patients to cope with their illness, thereby mitigating their desperation to receive a transplant. Thus, while the shift in services into the home has been a popular site of investigation for studies in the political economy of health and health care, when it comes to dialysis, this shift has an important, and perhaps unintended, outcome. For those with a spouse or family member to aid in their care, home dialysis

appears to mitigate patient desperation and improve their overall outlook on their illness and treatment.

In summary, the liberalization of services in Canada has had important implications for the delivery of services by affecting the ways in which patients and professionals experience the care environment. In the case of kidney transplant, there are a number of effects that can be seen in a review of the findings. First, there appears to be an emphasis on self-care and viewing patients as clients who are not only capable of making decisions regarding their health, but are also accountable for the success of treatments. This is evidenced by placing the responsibility of graft success on patients who must commit to post-operative drug and lifestyle regimes, which can be challenging for patients. This is also evidenced in the relationships between patients and medical professionals, especially when the latter opt for professional neutrality as patients are thought to be rational actors who can make informed decisions that best suit their needs. Second, the administrative inefficiencies that exist in the system highlight a conflict in a system that aims to provide services to all who need them within an environment that contains private interests. Ultimately, these inefficiencies become the burden of patients who face long wait times as a result of an insufficient supply of kidneys. The effects of liberalized care can also be seen in participants' support for private sector care provision, particularly in terms of medical tourism. The commercialization of healing commodities is not only unchallenged by the users and purveyors of the public system, but is seen as a right for those who can afford to participate. Finally, there was at least one finding that diverged from arguments presented in the literature on the impact of structural transformation, and that was the benefit of home dialysis in mitigating patient desperation. This finding is perhaps an

important area of investigation for future work. Overall, it appears that ideological shifts towards liberalized models of care are apparent in the experiences of patients and medical professionals studied here. These experiences help to provide a better understanding of the influence of structural factors on patient decision making.

### **The Canadian Organ Buyer**

In addition to the structural influences that shape the experiences of patients and medical professionals involved in kidney transplant in Canada, there are other, though not dissimilar, ideological and global conditions that create and sustain Canadian participation in the organs trade. Sharp (2006) explains that medicine has the effect of alienating the self from the body in order to treat the “ill body” and its poorly functioning parts. In this way, bodies that are so objectified are easily appropriated for their instrumental or use value, as opposed to considering the intrinsic value that is possessed by all persons (Wilkinson, 2003). Pálsson (2009) defines this situation as the expansion of the productive value of bodies beyond labour, whereby production is possible through the production of an organ. Under a new ‘biotech’ mode of production, the body is an increasingly malleable thing that can fulfill the needs of particular individuals who live in a limitless world of medical possibility (Rabinow, 1996; Pálsson, 2009). Once a body is so objectified, it is then possible to create contexts within which the body can be broken down further and exchanged. Appadurai (1986) and Kopytoff (in Appadurai, 1986) explain that commodities indeed are social products, and humans can, therefore, create the social conditions in which any object can become a commodity, especially given that money is universally understood. When it comes to trade across borders, new contexts

emerge where the cultural frameworks protecting certain sacred objects break down. Sharp (2006) further identifies the historical tendency of humans to transfer exchange value onto the “socially expendable people” of the world, such as in the case of slavery. Scheper-Hughes (2003) argues that the spread and continued valuation of capitalist cultural frameworks, mixed with the spread and advancement of medical technologies, has led to the advanced consumption of expendable bodies. Additionally, globalization brought about the liberalization of states services, such that welfare state models continue to break down (McKeen & Porter, 2003). What has emerged, then, is a global socio-political class system that is designed to maintain the privileged position of those who already hold the power, wealth and health – whether it is through the extraction of resources from underdeveloped areas or through the development of ever more advanced technologies (Wallerstein in Seidman, 2009). Medical technologies and treatments that are often inaccessible to those living in the developing world are offered up as part of deluxe resort vacations to the global elite (Scheper-Hughes, 2002). Cohen (2002) asserts that with this new culture of (medical) consumption, there is a necessary suppression of recognition whereby sellers are regarded as “same enough” to provide resources, but not so same as to threaten the conscience of those obtaining the resources. He states that the desperation to preserve a privileged class necessitates a state of exception where the worth of an organ seller cannot be called into question. In the present historical moment, relationships between people are economic to the fullest extent. Additionally, a lack of respect for human dignity and equality, a desire to uphold individual choice, freedom of action and will for the already powerful, and a selfishness encouraged in private economies that bend to the whim of client demand, combine to make self-preservation the

ultimate goal. Self-preservation is made achievable through the consumption of foreign, poor, marginalized, other kidneys. When it comes to obtaining organs that are in short supply, perhaps we seek to find the best option of freeing ourselves from our burden because we can afford to. Based on the literature mentioned here, we find that Canadians are indeed likely participants in the trade, are “potential buyers,” by virtue of their relative affluence and desire.

Despite these social and cultural conditions, which Scheper-Hughes and others claim create potential organ buyers, an analysis of the findings of this study reveals that this perhaps it not an entirely accurate picture of patients waiting for donated kidneys. For example, none of the patients interviewed had, at the time of the interview, chosen to buy a kidney abroad; however, all participants were able to identify cases where other patients had travelled abroad, with varying success. From the perspective of medical professionals, very few patients make the choice to purchase a kidney abroad compared to those who stay and wait in Canada, but it does happen. Still, all patients identified conditions under which they would consider travelling abroad to purchase a kidney, which is the focus of the following subsection. As I argued elsewhere, the conditions of participation help to highlight the values that are held in the highest esteem by patients and medical professionals involved in organ transfer in Canada. Through these conditions, we are able to identify the circumstances under which a patient chooses either to commodify or not commodify the body of the other, that is, when they choose consumption over non-consumption. The conditions of participation are then also tied to considerations of exploitation of the bodies of impoverished others who are the global organ suppliers. If, as the literature argues, bodies are indeed dehumanized and stripped

of meaning in a liberal, medical, capitalist world and they are subsequently commodified, then patients should be able to identify conditions under which they would go through with purchasing a kidney, that is, they would become “potential organ buyers” by virtue of their relative affluence and desire. On the other hand, if there are no conditions under which patients would travel abroad to purchase a kidney, then perhaps bodies are not so commodified and further analysis is required.

### *Conditions of Participation*

Based on the findings presented in the previous chapter, it appears that those who could not afford to participate in the trade were more likely to say that they would in the future. These patients were capable of providing clear conditions for their participation as they identified what would need to happen in order for them to participate in the trade, such as making or saving up enough money. Patients who could afford to participate also identified conditions for participation, such as a guarantee of safety; however, they felt that since such conditions were impossible to meet, they would not participate. When patient responses are combined to include both the “meetable” and “unmeetable” conditions, all patients expressed similar concerns. For example, all patients identified financial ability, a guarantee of quality and safety, trust in the transplant team, and location as significant factors. Medical professionals further added the conditions of severe desperation to get off of dialysis, the absence of a living donor, the influence of family and stage of life pressures on typically middle-aged men, and the duration of time spent waiting. Thus, there are indeed a number of conditions for participation that have

been identified by both patients and medical professionals, and these need to be considered in terms of their broader social and cultural influences.

Patients' "conditions for participation" are comprised of self-centered concerns and motivations. First and foremost, patients expressed a deep concern for personal safety. They were also concerned about cost, and about being able to trust the doctors involved in their treatment. Medical professionals identified similar self-centered motivations such as hating dialysis, and feeling social and economic pressures to maintain a "bread winner" position in their family. Importantly, self-centered concerns and motivations do not express a concern for others. The omission from the conditions of participation, then, is any condition which would recognize the person providing the kidney in the exchange. Indeed, not one patient identified a concern for kidney sellers as a significant factor that would influence their decision to travel abroad. A list of conditions that omits a concern for others is telling in terms of the dominant values that underlie decision making when it comes to participation or non-participation.

Recall from the previous chapter that all patients demonstrated a low concern about the exploitation of the poor involved in organs trade and trafficking. Only two patients were concerned about what would happen to their money once they had paid for a transplant. A concern regarding the fairness of an economic exchange is arguably not an entirely humanistic concern. For example, one patient was concerned that the seller would not get his or her fair share of the money, while another felt that the sellers would squander their earnings. In both of these cases sellers are regarded as rational economic actors, as a person in an economic exchange who has particular responsibilities; to receive appropriate payment for their "labour" and to not misuse earnings through unwise

purchases. This understanding of organ sellers is important as it does not fully acknowledge the impoverished position of kidney sellers; selling a kidney is an act of desperation to survive (Scheper-Hughes, 2003). In other words, there is concern about the equity of an economic exchange, but not about the person or the factors which led the person to reach such a level of desperation. The relationship that a patient imagines having with a kidney seller is based on an economic relationship, rather than on any kind of personal relationship. Patients, thus, lack concern about the exploitation of the global underclass; kidney sellers are seen as fully capable of engaging in economic exchanges free from broader social and political forces that maintain their low-class position. Importantly, patients do not consider the highly coercive force that economic insecurity can create for people in the developing world. Overall, the concerns that are expressed in the list of conditions for participation do not involve a concern for others, but rather demonstrate a tendency to relate with unknown global others through economic terms, as opposed to developing any kind of personal, social or even moral relationship.

It is important to restate that medical professionals demonstrated a range of concerns regarding exploitation, and a few highly concerned medical professionals identified exploitation as a significant problem; however, most did not feel that expressing a particular value position in regards to exploitation was within their role. As a result, almost all opted not to discuss the exploitation of the trade with their patients. Given that medical professionals educate their patients on their health status, on understanding their illness, and on lifestyle changes and treatment options, but choose to omit exploitation in organs trade, it is likely that patients are not made aware of, nor are they encouraged to consider, the implications of the choice to travel abroad. Furthermore,

perhaps it is because medical professionals show the greatest concern about the personal risks of buying organs abroad that patients become similarly focused on self-centered factors. Understandably, patients facing the challenges of renal failure and dialysis have much to consider, the least of their concerns might be their answer to the question “is it wrong to buy a kidney?” Still, perhaps too many patients do not fully consider the implications of their actions and this may be because they are not encouraged to do so. Despite the fact that medical professionals demonstrated a greater range of concerns about exploitation, a need to recognize the marginalized position of poor organ sellers does not appear to be communicated to patients.

Considering the literature presented here regarding the nature of organs trade and the relationship between wealthy organ buyers and poor organ sellers, it appears that Scheper-Hughes’ and others’ evaluation of the present situation is at least somewhat accurate. Insofar as the dialysis patients interviewed are part of a liberal market economy which dictates particular ways of acting and interacting, and determine what knowledge is known and by whom, patients appear to exhibit a lack of concern regarding the coercive force that economic deprivation creates in the third world. Perhaps patients do not have a clear understanding of what organs trade is and why it is exploitative; however, it should be reiterated that they were given examples of exploitation involved in the trade during the interviews and even with a more clear understanding of exploitation, self-preservation was the first and foremost concern, over and above all others. Thus, patients appear to not recognize those who are removed from their experiences of the every day, including poor organ sellers. Considering that the broad theoretical question of this work is “are we consumers or are we altruists?” these findings provide a partial answer. The patients

interviewed here had not participated in the trade, and, based on their concerns, likely never will. While patients may not be “consumers,” based on their chosen path of kidney procurement, they do exhibit many of the tendencies of society which embraces liberal ideologies and which supports the commodification of the body. The conditions that create potential organ buyers are indeed present in Canada.

It is, however, also important to consider the formation that organ transfer takes within Canadian borders to understand why more Canadians are opting to stay and wait for donated kidneys. Notably, Canada’s institutions for organizing organ transfer are committed to social responsibility; they are based on an altruistic, voluntary donation model. There is strong support in the literature that institutions that organize the collection and distribution of human products are built upon and reflect significant social and political features of society. Titmuss’ (1970) work supports the argument that the ideological traditions of a society shape the political landscape that defines health care legislation, and, at the same time, have significant influence on the users and purveyors of that system. According to this theory, then, Canada’s system reflects particular values that are presumably present throughout the whole of Canadian society. According to Titmuss, these values include a humanistic desire for social reproduction and cohesion; values that are in opposition to those embraced by liberal ideologies. It is important, then, to consider how and why these opposing values sets exist simultaneously in the Canadian case, and, depending on the types of systems that patients and medical professionals support or oppose, we may further understand where Canadians fit in the consumer-altruist divide.

***Organ Transfer Systems: Supported and Opposed Institutions***

As demonstrated in the previous chapter, patients and medical professionals expressed a certain amount of ambivalence towards the current opt-in donation system in Ontario specifically. The dominant feeling towards the system was that “it is just the way it is”. Regardless of their level of knowledge about how the system functions, patients felt that those on wait lists for donated kidneys do eventually receive a transplant; however, they also felt that the wait is far too long. Patients also recommended a number of improvements to the current system that would make it more effective. These tended to focus on factors of a social nature. For example, patients felt that more could be done to capture potential donors, such as through public education because people who are unaffected by renal failure are not aware of, and do not care about, organ donation. Similarly, medical professionals shared the sentiment that the system is all we have and is “the best we have;” however, they felt that more work needs to be done in order to enhance the system. As mentioned earlier, the administrative barriers that make the system inefficient appear to be the result of the influence of both public and private interests. When governments are unable to provide resources for particular health services, resources are misallocated, or resources are allocated based on the interests of particular groups, inefficiencies arise in the system that are difficult to rectify. Inefficiencies caused by a mix of public and private interests tend to be passed on to patients who must wait for an average of four to six years for a kidney transplant. Medical professionals also made clear that while change in the system is happening, it takes time that ill patients often do not have. Overall, the participants were equally committed to the processes of the donation system; however, they did express ambivalence towards its effectiveness.

Despite this ambivalence, some participants identified aspects of Canadian health care generally, and organ transplant specifically, that are relevant to a discussion of values, including the universality of care, fairness and equity. Participants made statements such as “everyone lines up,” and pointed out that no one is able to obtain services or treatments that another cannot by virtue of their income. The dominant values of universality, fairness and equity were apparent and have been part of health care legislation since the implementation of the Canada Health Act 1984 (Swartz, 1998). Interestingly, however, it became clear throughout the interviews that these institutionalized values do not necessarily reflect those permeating social life outside of institutions of care. For example, patients felt that people do not register to donate their organs because they do not care, they are selfish, they are not aware of the need, they are not being educated and may simply be too busy in their own lives. In fact, the majority of patients admitted that prior to becoming ill they were not donors, nor had they considered donating their organs. Based on these personal accounts, patients appeared to be torn between blaming the public for not adhering to the values that are fundamental to the system, but at the same time, not blaming them because they themselves had adopted the same behaviour in the past. There was an apparent hopelessness expressed about this arrangement; patients felt that little can be done to increase caring and that even awareness-building would likely have no impact on the number of available organs. Based on patient responses, it seems that the shortage of willing organ donors in Canada may be the result of a society that does not share the values that are supported in and determine the organization of the system. Overall, participants acknowledged that the current system may be the best strategy, but they felt that it is unlikely to ever be

perfected; patients will always have to wait. This may be particularly true if the values of the system remain outside of, or perhaps even in opposition to, those circulating in society broadly.

The finding that institutional values do not necessarily match broader social values appears to challenge Titmuss' thesis that because Canada has a tradition of a voluntary, altruistic donation system, there is a broader commitment to social reproduction and cohesion. However, to say that Titmuss' theory is false would be incorrect. Titmuss was able to empirically demonstrate the consequences of a system for organizing blood and blood products that supports market-based transactions. He found that relying on a blood supply obtained from members of society who are enticed by payment endangers the lives of those requiring transfusions. Further, such a supply is indicative of a system that preys on the most marginalized populations. From this Titmuss argued that systems which create opportunities for citizens to be altruistic tend to have a far healthier and sufficient blood supply and also demonstrate a broader commitment to social responsibility; everyone must give in order to maintain a healthy society of people who care for one another. His findings are compelling and while he may be correct in his assertion that donation and altruism are "good for society", it ought not to be assumed that on an individual level, members of that society hold such values in high esteem. Simply because the current organ transfer system relies on altruistic donors does not mean that such donors are available. Perhaps citizens do not want to be relied on to become organ donors. It is, of course, the role of institutions to "create" or "generate" donors from within the population (Healy, 2006), and Trillium takes on this role in Ontario with its positive messages and campaigns. Still, as all participants to this study expressed, it is likely not

enough. The apathy circulating in the public regarding organ transfer reveals that there may not be a strong commitment to the ideals that the system upholds. Thus, patients and medical professionals were generally ambivalent toward the current system's functioning and effectiveness. It was felt that organizing organ transfer through opt-in donation, with the aid of organ procurement organizations and medical teams, was simply "the way it is," but perhaps does not reflect dominant social values, and perhaps is not the most effective way of procuring transplantable organs.

We can further identify the values circulating in Canadian society through a discussion of other forms of organ transfer, the first of which is opt-out systems. Most participants in this study supported opt-out systems. They felt that such systems force potential donors to become aware of the issues, while individuals who do not want to donate must actively opt-out of participation. Interestingly, it was clear that from the participants' perspectives, an opt-out system would never work in Canada because it does not uphold individuals' fundamental right of freedom of choice. In fact, opt-out was regarded as too politically contentious to ever seriously be discussed in a Canadian context. As mentioned earlier, in many countries, including the United Kingdom, these systems are not seen as viable because they are paternalistic and of an older, welfare state, era (Organ Donation Task Force, 2008). Whether a nation adopts or abhors presumed consent may indeed point to the way individuals and governments value government intervention in the lives of citizens. Though not a focus of this analysis, it is interesting to consider the difference between countries which either support or do not support this form of organ transfer. Based on the participants' perspectives highlighted here, it appears that Canada will likely never see an opt-out organ transfer system, despite its potential for

increasing the number of available organs, likely due to its perceived imposition on freedom of choice.

Turning now towards a more liberal mode of organizing organ transfer, incentivized donation, which includes both non-monetary (or hidden) or direct monetary incentives, we can further understand how dominant social values play out in the implementation of liberal forms of transfer. Healy (2006) argues that non-monetary incentives are inevitable in voluntary donation systems in liberal market economies as a result of an ever increasing need for organs and a prevalence of economic relationships over personal relationships. He also argues that non-monetary incentives would be concealed within the rhetoric of gift giving, since organ procurement organizations have emphasized the value of giving rather than getting for so long. Interestingly, participants felt that non-monetary incentives would likely have no impact in terms of increasing donation because they would not be considered valuable enough to sway those who truly do not want to donate. Also, the rhetoric of gift giving continues to be strong in Canada and, as Healy argued, will likely never change. It appears, then, that Healy's theory on the inevitability of non-monetary (or hidden) incentives is inaccurate as, at least until this point, incentivization in the system has not occurred. Thus, despite arguments for the power of non-monetary incentives in increasing organ supply, implementing such incentives in organ procurement was not supported among the participants.

Interestingly, monetary incentives were regarded as being a likely more successful strategy. Some medical professionals pointed out that people engage in activities that involve "selling" bodies and their productive value every day. For example, there are those who are paid to put their life at risk, such as police officers or soldiers, and there are

those who are paid for sex, such as prostitutes. From this perspective, some medical professionals felt that buying organs, particularly through a government regulated system, is no more wrong or dangerous than these other common activities. The majority of participants, however, felt that a government regulated system would never be supported by the public, though they had difficulty explaining why society would never accept the exchange of money for organs. Perhaps this was the result of a conflict between the opposing value systems that exist in society generally. Participants understood that the public would never accept the commodification of organs within Canadian borders. Still, participants felt that monetary incentives would likely have more power to entice people to donate their organs than non-monetary incentives; however, they felt that this would never be supported by the Canadian public.

Based on the pervious discussion regarding a lack of support for monetary incentives in Canadian society broadly, it appears that organs are somehow different from other common consumption items. Both patients and medical professionals expressed unease throughout the interviews when discussing commodifying body parts within Canada, and most felt uncomfortable discussing the issue. Perhaps this unease was a result of participants' knowledge that getting an organ requires a sacrifice of some form and, ultimately, transplant is not to be taken lightly. According to those interviewed in this study, Canadian organs are not commensurable, or at least ought not to be exchanged for money; they are different from other consumption items like a "tank of gas" or "bag of milk." Recall that Healy (2006) argues that there is a significant fear of the danger of commodification; that should human parts be considered like other common consumption objects, subjected to the forms of market interaction and rational and economic cost-

benefit analysis, then society loses sight of something more, something perhaps too complex to explain, but something human and powerful. He states that if institutions were to support the practice of commodifying the body, there may be, from the public's perspective, an unattractive quality being reflected back onto society, something that may be threatening to the reproduction of positive social values. Participants' lack of support for incentive systems in Canada appears to support this theory. While they had difficulty expressing why market-based systems were wrong, they were strongly opposed to the implementation of such systems.

To summarize, Canada is a capitalist country that operates on the basis of neo-liberal ideologies, and it is therefore not difficult to imagine that values that underlie practices that treat bodies as objects and commodities are indeed prevalent across many areas of society. These values are mainly individualism, privatization and economic exchange. Still, based on the data gathered in this study, it appears that support for the current opt-in system, if only for the simple fact that "it is what we have," is relatively strong in Canadian society. It can also be considered the best, morally, socially and politically appropriate system; however, participants were ambivalent towards the Canadian system that is slow to react to the need of patients. While participants were mostly in favour of implementing opt-out systems, they felt that Canadians would not support such an imposition on their freedom of choice. Further, participants expressed the notion that governments ought not to interfere with individuals' decisions regarding their bodies. Again, based on the participants' perspectives, Canadians also would not support non-monetary incentives for organ donation. It is important to point out that providing these incentives for donation is not regarded as a morally wrong activity, but, rather, as an

ineffective motivator that is not strong enough to sway those who do not want to donate. Canadians also do not support monetary incentives, and they particularly do not support any form of a market-based system within Canadian borders.

It is now appropriate to return to the broad theoretical question raised in the study which helped to develop the work presented here and that is, where do Canadians fit in terms of the consumerism-altruism divide? The value sets oppose one another and yet exist simultaneously in the present Canadian context. Liberalized welfare state medicine impacts the experiences of the users and purveyors of the system, whereby patients are seen as rational actors who are expected to take care of themselves when the system fails, such as through acquiring services and technologies through the private sector. While liberal ideologies permeate the care environment, it is also clear that similar ideologies permeate the social and cultural contexts of Canadians as both national and global actors. Further, evidence has been presented that Canadians participate in the trade in human organs. Both patients and medical professionals identify a number of self-centered concerns about organs trade, which result in patients staying in Canada to wait for a donated kidney. Though some participants identified the exploitation of organ sellers as problematic, overall, this was not a significant concern for patients facing long wait times for a transplant. If the conditions for participation were met, it is likely that many more would opt to purchase a kidney abroad in order to avoid the inefficiencies of the Canadian system. This is evidenced in participants' shared support for participation in medical tourism by those who can afford to do so. It thus appears that the conditions that create organ buyers are present in the Canadian case, a finding that supports the assertion that Canadians are consumers first, by virtue of their relative affluence and desire. Yet, an

analysis of support and non-support for transfer systems reveals that perhaps such an evaluation of patients waiting for donated kidneys in Canada is inaccurate. As discussed, Canada has a voluntary, opt-in organ donation system which appears to enjoy a significant amount of public support. This is evidenced by patients' and medical professionals' evaluations of the system in comparison to the other systems mentioned. The present system is considered the best option as it allows individuals to retain their freedom of choice; it allows them to choose to be altruistic. Unfortunately, this arrangement also allows for public apathy towards organ donation and while organ procurement organizations attempt to increase awareness and education, it may not be enough. Importantly, taking an opt-in approach to organs transfer removes the danger of commodification that market-based systems create. Though participants were ambivalent towards the current system, most were strongly opposed to a system that involves the exchange of money for organs. Thus, from this discussion, it appears that perhaps Canadians are not consumers, but they are discompassionate and sorry altruists.

### **The Foreign Kidney**

Canada is one of the wealthiest countries in the world. As a capitalist nation, Canada has developed a liberalized health care system that exchanges funds for human goods at points along the supply chain; however, the economic nature of medical services is hidden from the public. The liberalized medical system emphasizes "client" needs, holds individuals accountable for their own health and health related decisions, and encourages and requires citizens to seek out treatments in the private sector. Canadians understand that nothing is free and that anything is possible with enough money,

including travelling abroad to purchase medical services. At the same time, Canadians support an organ transfer system that is organized around particular social, moral and ethical standards, mainly universality, fairness and equity. While market-based organ procurement is not publically supported, there appears to be a simultaneous existence of contrasting viewpoints, such that we are in some ways both consumers and altruists. Organs are contested commodities, but perhaps there is still a question that remains to be answered, and that is, whose organs are commodifiable and whose are not? What this analysis reveals is that determining whether the act of purchasing a kidney is seen as right or wrong depends on the situation of the potential buyer, whose kidney is being sold and from where it is being obtained.

Canada is also a diverse, multicultural and multiethnic country. To essentialize all Canadians as white, western and affluent, as Scheper-Hughes does for example, is inappropriate given that what it is to “be a Canadian” varies greatly. Given that most of the participants were second generation Canadians, the conditions of participation that participants identified involved concerns for self-preservation above all else. It is important to consider that had the participants had a more intimate understanding of trade networks and processes, perhaps their concerns would be adequately alleviated and perhaps we would find more second, third or fourth generation Canadians participating in the trade. What is more, had this study included foreign nationals and recent immigrants, perhaps the findings would have been altogether different. For those who originate from countries where trade is prevalent, their desperation and their knowledge of the system may be enough to outweigh their concerns. Though there has been some evidence presented that a significant number of Canadians who participate in the trade are foreign

nationals or recent immigrants, it is not enough to draw any general conclusions at this time. While ethnicity and country of origin appear to be important to determining the likelihood of participation, they require further investigation. In acknowledging the role of ethnicity in participation, this study attempts to advance our understanding of the Canadian case. Those who essentialize Canadians as white, western and affluent and who fail to mention the role of ethnicity, fail to accurately capture all of the possible determinants of participation and, therefore, present an analysis that is not based in the experience of our time.

Importantly, markets in organs were not supported by those interviewed for this study, but this was not because of the likelihood of exploitation of poor people. Patients and medical professionals alike were apathetic about the exploitation of the global underclass in the organs trade. As discussed by Coburn (2006), materialist approaches to political economy question how relations of production play out between the first and third world, and how capitalist relations between nations influence the behaviour of individuals who look to engage particular economic relationships. In the case of organs trade, some argue that the relationship between first and third world actors involves the extraction of use value from impoverished bodies that are then consumed by wealthy bodies. This relationship is maintained through a removal of meaning of the other, foreign body and recognition of the other (Cohen, 2002). Difference, particularly difference in power and opportunity, is a necessary component in creating a state of exception for organ removal. While the patients interviewed in this study had not purchased kidneys abroad, their reasons for doing so were not based on their recognition of the class position of foreign sellers.

Taking this a step further, we can consider the situation where foreign nationals and recent immigrants become involved in organs trade, and we find that these arguments may still be supported. So far as foreign nationals and recent immigrants may be said to have relative affluence and opportunity compared to impoverished people in their home country, then perhaps they maintain class based productive relationships that existed in their home country but from Canada. As mentioned, medical professionals recognize the potential for this exploitative relationship when patients travel to their country of origin to purchase organs or when donors are brought to Canada for the purpose of extracting a kidney. Medical professionals also pointed out the tendency for individuals from either of these groups to avoid receiving organs from family members residing in Canada, perhaps as a result of their concern for familial wellbeing. Though more research is required, class difference and relations of production are involved in any situation where resources, in this case body parts, are extracted from one group of people and not another. A lack of awareness and concern about exploitation further removes the person selling an organ from the exchange, and it appears that ethnicity may not impact the degree to which class based difference and power are recognized.

What is clear, however, that foreign organs are perceived as different from Canadian organs. Patients on dialysis experience a significant amount of anxiety regarding their diagnosis, treatments and the time that they must wait to obtain a kidney in Canada. Some find themselves in a situation of extreme desperation to regain what they have lost; control, family, work, independence, etc. Perhaps those who choose to participate in the trade understand there are alternatives to a system that fails to provide adequate and timely services. Perhaps for these Canadians, desperation wins out over

other concerns, such as concerns for safety and trust, or desperation win out over a desire to uphold the values of the Canadian system. If the values of social responsibility, altruism and voluntarism that are upheld in the Canadian organ transfer system are not upheld elsewhere, then those who are able to afford purchasing a kidney can take advantage of the opportunity to commodify bodies through trade. That is to say, perhaps in countries that exist outside of the Canadian value system, the kidney of the foreign other has an entirely different meaning than the kidney from someone who is committed to a model of social responsibility. Based on this reasoning, and on the findings and discussion presented here, the message appears to be that *we ought not to commodify Canadian organs, but the organs of foreign others, in faraway places, hold potential for commodification*. Overall, foreign organs belong to dissimilar others that are not committed to the same values and, therefore, exist in the state of exception, in a world removed from the reality of the clinic in Ontario, Canada. To bring us back to the main theoretical insight that this analysis seeks to provide, it appears that we are altruists within Canadian borders, but are consumers in a global context.

## **CHAPTER 6: Conclusion**

The buying and selling of human organs is illegal. This is because using the bodies of others goes against the moral and ethical standard of upholding human dignity. As Kant argued, we ought not treat others as means to an end, but as ends in themselves, for if we treat others as means to an end, we remove the value of the individual, and the value of their life, from existence. Unfortunately, the world has come to a point in its development where the conditions have been created to commodify human organs, particularly for and by those who have the power to purchase them. Desire for the bodies and organs of the other and the desire for life itself find avenues for expression in the form of markets in human goods. Markets exist in the developing world, where the institutions that would serve to protect the vulnerable from such exploitation do not fulfill this role. Those who demand organs both in the developed and developing world, who cannot obtain them through government sponsored organizations, grab hold of the opportunity to fulfill their need through the exchange of money for organs. This liberalized form of health care is indeed encouraged in most market economies today. There are a range of motivations that drive individuals to purchase an organ rather than go through the accepted institutional arrangement, and how one evaluates this opportunity to purchase a needed organ is an important area of sociological investigation. There are many factors influencing the decisions that patients make when it comes to obtaining needed organs. Given that patients make decisions in a complex social, political and economic nexus, this study sought to unravel exactly what factors influence patients' decision making and in what way. This study aimed to determine how and why Canadians come to participate in the international market for human organs and how the system of

organ transfer that is available to Canadians affects the decision making process.

Although the patients interviewed for this study had not travelled abroad, some mentioned they would consider it and all expressed self-centred conditions that would have to be met in order to participate. Thus, while patients exhibited an overall aversion to participation, arguably, if it were possible to meet their conditions for participation, patients involved in this study would likely purchase a kidney abroad if it meant they did not have to wait.

Based on the literature presented, in combination with the data provided through interviews, it appears that Canadians come to realize their role as organ buyers as a result of a few key factors. These factors include both a concern for self-preservation and desperation. In the case of foreign nationals and immigrants, these factors also appear to include knowledge of trade networks and processes as well as desire to not harm family living in Canada. Institutions of care may help to create these factors in that while they attempt to increase the number of available organs, they face a number of challenges, which are due to the existence of both public and private interests. In a liberalized care environment, patients come to value the right to achieve health outcomes by whatever means necessary, including seeking out services in the private sector. Interestingly, the patients interviewed in this study did not support the implementation of a market-based system in Canada, which appeared to be due to a fear that commodification at the institutional level will disrupt society's commitment to the values of fairness, equity and universalism. Thus, while there are indeed a number of ways in which broad ideological shifts in health care have impacted the activities and perspectives of patients waiting for donated kidneys, there is an interest in simultaneously upholding values that are in opposition, those of consumerism and altruism.

When it comes to international organs trade, participants in this study were generally unconcerned about the exploitation of poor people. Further, participation in the international organs trade was not as critically evaluated as the implementation of a market-based system in Canada. Like medical tourism, participants felt that the trade is an option for those with the money to participate. Thus, while it seems that in Canada it is not right to commodify organs through a government regulated monetary incentive system, buying the organs of foreign others is a different process with a different meaning altogether. Foreign organs exist in a place that is physically, culturally and socially removed from the everyday lives of Canadian citizens, and from a commitment to strong social and moral values.

This study took a meaning-centered, political economy approach in order to begin to identify the “Canadian position” in terms of dominant values which underscore the processes of organ transfer and trade. It focused on the perspectives of twelve patients and medical professionals involved in a kidney transplant program in southern Ontario, a majority of whom were at least second generation Canadians. Of course, the perspectives analyzed here may not be representative of the perspectives of all Canadians, particularly given the differences between each province, region, city, or community. For example, southern Ontario is the most densely populated regions of the country and is home to the highest proportion of new immigrants. The participants of this study, then, may not share the experiences, culture and ideologies of rural Canadians. The participants may also not be representative of Canada’s indigenous populations who may experience additional challenges when it comes to accessing health services. Additionally, a significant portion Canada’s population was not born in Canada and many immigrants upon arriving in

Canada do not immediately or ever assimilate the common activities, lifestyles and values of second or third, or even fourth or fifth generation Canadians. The diversity of the Canadian population is still more complicated by the number of spoken languages, religions and cultural practices, which make it difficult to extend the experiences and knowledges captured in this work outwards to include all other Canadians.

Still, the perspectives captured in this study provide a useful starting point for exploring how practices of organ transfer influence decision making among patients when it comes to procuring needed organs. As well, evidence has been presented that individual actors operate within a particular social context. Today, Canada is a liberal market economy which organizes its health care system around market principles. The organization of health care and society broadly are taken for granted and do not appear to be problematic on the surface until individuals experience the unintended consequences of an instances on economic relationships over personal or moral ones. The experiences of the users and purveyors of health care are thus particularly valuable in understanding how capitalist ideologies, such as an emphasis on the individual, affect the daily-lives of citizens. By taking a meaning-centered, political economy approach, we can investigate the impact of broader ideological shifts through understanding individual experiences “on the ground.”

Another limitation of this study is the omission of participants who have either participated in the trade in the past or who are actively engaged in participation. These perspectives would be highly valuable for a discussion of values and factors influencing the decision to travel abroad rather than waiting for a donated kidney in Canada. Unfortunately, such a population of participants is difficult to identify and approach for a

number of reasons. First, they must engage in trade activities outside of the health care system and, therefore, are less likely to be accessible through that system. Second, patient confidentiality protects these individuals from being named should their primary physicians know of their activities or intentions. Third, it may be the case that these individuals are less likely to self-identify for fear of criticism. Despite these challenges, researchers could seek to capture this population through public media and potentially through the use of online networks and forums should they exist. Still, although the voices of those who have or are actively engaged in organs trade are missing from this analysis, the perspectives presented here of waiting patients and their care givers provides valuable insight in terms of unraveling the factors that impact patient experience and influence the management of their care.

As mentioned in the previous chapter, future research could investigate the prevalence of foreign nationals and recent immigrants in terms of Canadian participation. Further, such research could also seek to elaborate on the role of concern for familial wellbeing, particularly among new Canadians, as it may also be a significant factor in determining the participation of individuals from these groups. This would help to further advance the literature on buyer participation in the international trade in human organs, recognizing the diversity of North American societies and avoiding the essentializing nature of current conceptualizations.

Future research could also seek to expand the representation of patients and medical professionals by drawing perspectives from those involved in transplant programs across the country. Each provincial transplant program is somewhat different and a study which takes into account this difference, such as through the use of sampling

across programs, would arguably provide a much broader understanding of dominant values and of the ways in which these are expressed through varying forms of organizing organ transfer. It might, however, be the case that the lifestyles that create the conditions for renal failure are more common among individuals living in densely populated urban centres, which would make urban centres the best sampling location. Still, capturing the perspectives of waiting patients and their caregivers from a variety of regions would likely serve as a valuable addition to the work presented here. Thus, a greater range of comments on processes of organ transfer and perspectives on organs trade would expand the knowledges and experiences outside of those who are more typically living the urban Ontario life.

This analysis also focused on the perspectives of those involved in kidney transplant as opposed to transplant in other organs. As mentioned, kidneys are the most common organ bought and sold because a seller can live with one. Also, the demand for kidneys far surpasses the demand for others organ, due to the connection between lifestyle, obesity and kidney disease, to name a few factors. Still, future work could look to identify cases where patients travel for other transplant services or for other non-transplant services generally. This would involve a deeper investigation into the interplay of values in the practice of purchasing medical services in other countries, such as through medical tourism, as opposed to taking part in the socially and politically supported medical system in Canada. Such an analysis might also help to provide a more complete understanding of the ways in which patients' self-care activities are related to liberalism in Canadian life.

As mentioned in the previous chapter, there was one finding that appears to diverge from the literature regarding the consequences of the shift of care out of clinics and into the home or community. Armstrong and Armstrong (2003) discussed the impact of this structural change on women who tend to carry the burden of home or community centred care. While the perspectives of spouses of patients on home dialysis were not under investigation in this study, home dialysis has a number of benefits that are worth restating. Patients doing home dialysis tend to dialyze at night while sleeping, which allows many of them to take part in everyday activities such as working and raising a family. Because dialysis plays a somewhat diminished role in their lives, they tend to have more positive attitudes towards their illness, their treatments and their wait to obtain a kidney. Most importantly, home dialysis appears to lessen the desperation that patients feel, which is likely beneficial for spouses as well. The shift of care into the home in this case was the result of a need to reduce costs in health care, such that by removing patients from the clinic, patients are not reliant on expensive hospital resources and nursing staff. Home dialysis also has some drawbacks, such as the danger that patients can face when something goes wrong and a professional is not present. Still, in the case of the shift of dialysis into the home, it appears that there may be a number of positive outcomes that are particularly true for those receiving care. However, considering the research conducted by Armstrong and Armstrong, there is an opportunity to investigate further what impact the shift of hemodialysis into the home has had on families, spouses and other home care providers.

Overall, all Canadians ought to consider their role in unequal, unfair and exploitative exchanges around the world. Having relative affluence and being in a

position of power, Canadians are afforded opportunities that on the surface appear to provide wanted and needed services; however, actions have consequences. Participating in the trade in human organs is dangerous, not only for buyers who may receive low quality treatments in unsanitary conditions, but also for sellers who may wind up losing their life, or who may never be able to work again due to chronic pain and illness. Participation in the organs trade is also dangerous for another more humanistic reason. When we find ourselves valuing one life over another, degrading humanness, erasing a person's existence for the benefit of another's, we lose something that is difficult to explain, but is powerful nonetheless. We lose the value of human life, which is really all we have.

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## APPENDIX A

## Summary of Research Questions

**1. Questions relating to participation in organs trade among patients waiting for donated organs:**

- Are Canadians waiting for donated organs aware of the international market in human organs?
- And if they are aware, are they concerned about where organs come from, i.e. about the exploitation of the global underclass that is tied to their procurement?
- Under what conditions would someone participate in the market for human organs?

**Broad theoretical question:** Are Canadians consumers or altruists? How do we know?

**2. Consider current organ transfer strategies and perspectives of their users and purveyors, as reflective of dominant social values:**

- What do people think about the current organ transfer system in Canada, and is it doing what we want and need it to do?
- What challenges exist in this system for people who need a kidney transplant?
- And finally, how effective is this system versus the alternatives?

## APPENDIX B

Interview Guides

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## Medical Professionals

1. Can you briefly describe your relationship to organ transplantation, procurement, etc.?
2. Can you tell me a bit about the organizations and other people here at the centre involved in the transplantation process, from donor to recipient?
3. What do you think about the claim that we have an organ shortage in Canada?
4. Given that we currently have an Opt-in organ donation system, what are your thoughts on having an Opt-out system instead?
5. How do you feel about organ donation as a supply strategy?
6. From your perspective, how effective is the Trillium Gift of Life Program and the hospital covering the recipient side?
7. What would you say are some of the costs associated with organ procurement, first to the patient and their family, and to the medical system as a whole? Is there room for improvement?
8. [*Can you identify some alternatives to donation programs like Trillium Gift of Life?*]  
What do you know about organ markets/purchasing organs locally or internationally?  
How do you feel about organ markets/purchasing organs abroad or locally?
9. How are organs markets more or less effective than a provincial donation program?
10. Under what circumstances do you think someone would pursue obtaining a kidney through the market?

11. Is there a point where a Dr. or a transplant team would tell a patient, “look you have had three transplants, you’ve been on the wait-list three times, there’s nothing else we can do for you”?
12. What kind of information would you provide a patient wanting to pursue purchasing a kidney?
13. What are some of the characteristics of people who decide to go abroad?
14. In your experience, do patients have expectations about the success of a transplant and/or a treatment? Can you describe some common expectations?
  - a. Where do you think those expectations originate?
  - b. From what you can tell, what, if any, is the relationship between the messages that organ procurement organizations distribute out to the public and patient expectations?
15. Like many places, we have an anonymous donation system. How important is anonymity to the program, and donation generally? Who benefits? Could we do it another way?
16. Why do you think a market is not recognized as an organ supply solution by the federal or provincial governments?
17. How do you think the federal government should address um, or should it address the fact that Canadian do travel abroad and purchase organs and find ways around the system?
18. Are you familiar with the term “medical tourism”?
  - a. What do you think about the practice of medical tourism?
  - b. Do you think that it should be allowed?

c. Do you see any problem associated with the practice?

19. Some say a market in organs is inevitable but that it might simply look a little different than a overtly economic exchange, so not cash for organs but incentives, like the government the funeral costs or contributions to life insurance plans. What do you think about that claim?
20. Do you have anything else to add that would be pertinent to a discussion like ours that you have not mentioned?

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Patients

1. Are you currently on the provincial organ donation waiting list?
2. May I ask how old you are?
3. What kinds of treatments are you receiving right now for your illness?
4. How do you feel about being on dialysis/your treatments?
5. What does getting a kidney transplant mean to you?
6. When you first learned that you were ill, did you have any expectations about treatments or about transplantation? Can you describe them? Where do you think those expectations came from?
7. Have you ever heard the claim that we have an organs shortage? [*Surprised? Why a shortage?*]
8. [*Do you know how we get our supply of organs in Ontario, and in Canada generally? Do you know how the donation system works? Do you know what having a donation system means?*] So, from your perspective, how effective is our donation system in collecting the supply of organs to be transplanted?

9. How do you feel about organ donation as the chosen strategy for supply in Canada? Is it a good strategy? Is it doing what we want it to do?
10. Based on your experience, what are some of the costs associated with needing a kidney?
11. From your perspective, what might some of the costs be on the other side, so for organ donors and their families?
12. Given that we currently have an Opt-in organ donation system, what are your thoughts on having an Opt-out system instead?
  - a. How might an opt-out system be more or less effective than the provincial donation system?
  - b. There has been research showing that people, I know in Ontario for sure, are not supportive of an Opt-out system. Why do you think that is?
13. What do you know about markets and purchasing organs?
  - a. How do you feel about the practice of purchasing organs, rather than getting a donated one? How do you feel about people doing that?
  - b. How might organs markets be more or less effective than the provincial donation program?
14. Would you ever consider purchasing a kidney?
15. Do you feel that purchasing a kidney is an option for anyone who needs one?
16. Why do you think exchange for organs or a “market” is not the chosen supply strategy in Canada?
17. Some say that a market in organs is inevitable but that it might simply look a little different than an overtly economic exchange, so not cash for organs but incentives,

like the government helps with funeral costs or puts some money towards life-insurance. What do you think about that claim?

18. There are writers who say that in Canada we are kind, that we value things like fairness, altruism (which is giving for no personal gain) and voluntarism. And they say that it's because of our values that we have a donation system. We value giving highly, and we would never support a market system where people are buying and selling body parts. But at the same time, we seem to have a donor shortage...so what do you think about that claim that we as a people value altruism and giving? Is that still true?
19. Are you familiar with the term "medical tourism"? [*i.e. when people travel to other countries in order to access medical treatments not available in their home country, usually involving significant financial cost*]
- What do you think about the practice of medical tourism?
  - Do you think that it should be allowed?
  - Do you see any problem associated with the practice?
20. Do you have anything else to add that you think would be pertinent to the discussion that we've just had that you haven't mentioned?