ORGAN DONATION AND TRANSPLANTATION:
Considering International Policy Options for Canada

A Thesis
Submitted to the Faculty of Graduate Studies and Research
In Partial Fulfillment of the Requirements
For the Degree of
Master of Public Policy in Health Systems Research
University of Regina

By
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Regina, Saskatchewan
September 2012

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Michael Wakeham Sherar, candidate for the degree of Master of Public Policy in Health Systems Research, has presented a thesis titled, *Organ Donation and Transplantation: Considering International Policy Options for Canada*, in an oral examination held on August 8, 2012. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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*Not present at defense
Organ donation is the most cost-effective, if not the only, option for the treatment for end-stage organ failure. End-stage organ failure is an epidemic, costing the Canadian healthcare system over $35 billion dollars per year. As organ donation and transplantation (ODT) is the most cost-effective solution, it is in Canada’s best interest to maximize the number of donors to allow for the maximum number of transplants. Canada currently lags behind most developed countries and the literature describes most of the world being in an “organ shortage”, with demand for transplants far exceeding the supply of viable, donated organs. Current efforts are improving donation rates, but not at the same magnitude that demand is increasing.

Other jurisdictions use different operating principles to guide their ODT systems and achieve better results. Canada operates under a requested consent operating principle, where donors are required to volunteer their organs to be considered for transplantation. Many nations in Western Europe operate under a presumed consent operating principle, which reverses the onus and assumes everyone is a willing donor and individuals must specify their desire to not be considered. New and innovative operating principles have also been put into practice around the world. Israel operates under a reciprocal altruism operating principle where individuals who are willing donors, or are first-degree relatives of willing donors, are given priority ranking on the waiting list if they are ever awaiting a transplant. Iran operates under a legitimate market-based operating principle, allowing individuals to sell their kidneys (legalizing the clandestine practices that currently occur worldwide).
ABSTRACT

These operating principles are assessed for their ability to be implemented in Canada, as measured by their viability in the current political regime, their compatibility with the current policy framework, their legal viability and their ethical considerations. The operating principles are also assessed for their efficacy in improving the supply of donor organs. The reciprocal altruism operating principle carries too many legal and ethical barriers to be viable for implementation, and lacks strong evidence of efficacy. The legitimate-market based operating principle shows strong results (Iran is the only jurisdiction in the world without a waiting list for kidney transplants), but ultimately carries ethical burdens that would not conform with the values held by the majority of Canadians. The presumed consent system is highly championed in the literature, and is well suited to the Canadian political and legal environment, but evidence suggests it would require changes in how it is applied (changes that run contrary to any country currently under that operating principle) in order to have any impact on the number of transplants performed.

The province of Saskatchewan is the poorest performer in Canada by a large margin. Thus it is thoroughly assessed to pinpoint failures in existing policy and to find efficiencies that can be gained through greater co-operation among the provinces and through the co-option of best practices used by the top-performing provinces.
ACKNOWLEDGEMENTS

This thesis would not have been possible without the advice and guidance of my supervisor, Dr. Greg Marchildon. Funding for this research was provided by the Western Regional Training Centre for Health Services Research and the Faculty of Graduate Studies and Research at the University of Regina.
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CHAPTER ONE: INTRODUCTION

Does organ donation matter?

The front page of the February 3\textsuperscript{rd}, 2012 \textit{Regina Leader Post} carried a picture and headline “Family urges organ donations” (Warren 2012). The article details a Saskatoon resident’s choice to “help [his] family see the positive side in the ordeal” of his brother’s tragic death by having his kidneys, heart, liver, pancreas and lungs removed for use in transplant surgeries. His motivation to participate in the article was to “encourage others to explore organ donation with their families.” This article mirrors a regular stream of articles found throughout Canadian news organizations.

The \textit{Charlottetown Guardian} had an opinion piece under the title “How about signing an organ donor card? I did” in the January 28\textsuperscript{th}, 2012 edition (MacLean 2012). Relating the story of Sarah Burke, the Canadian Olympic ski champion who became an organ donor after her sudden and tragic death, the article expounded on the benefits of organ donation, rebuking participation rate among Canadians and describing Canadians as “bottom feeders when it comes to donating, with one of the worst organ donor rates of industrialized countries.”

Moreover, the \textit{Ottawa Citizen} reported on January 20\textsuperscript{th}, 2012 of the campaign to “raise awareness for organ donation” and to encourage “more people to... register to be organ donors” by soliciting the support of pop icon Justin Bieber through the social networking tool Twitter (Deachman 2012). These articles are simply the most recent examples in a longstanding public outcry about a major and perpetual deficiency in the Canadian health system. These
CHAPTER ONE: INTRODUCTION

type of articles in the popular media often cite pessimistic statistics about the never-improving state of organ donation and transplantation in Canada.

Despite advancements in medical technology and procedures, the situation in end-stage organ failure seems to be worsening. People are getting treatment earlier, are having better access to nephrologists, and are generally seeing a later onset of disease due to healthy lifestyle choices. Yet, in 2009, the incidence of end-stage renal disease in Canada was still triple what it was in 1990 (CIHI 2011). In fact, the rate of organ donation increased by over 28 percent between 1999 and 2008 in Canada, but “is not keeping pace with [growing] demand” (CIHI 2009).

Until the middle of the twentieth century, organ failure was a death sentence. If the damage outpaced or impaired the body’s immunological ability to repair it, there were few options. End-stage organ failure is when an organ no longer performs its required function and is impaired to the extent that only replacement will prevent death. Advancements in biomedicine and the clinical sciences now allow many vital components of a person’s biological machinery to be replaced like mechanical or electronic parts.

Given that organ replacement via transplant is well within the realm of medical possibility and given that the procedures are well documented and well understood, end-stage organ failure is often a treatable condition. Despite this, Canada is still ineffective in meeting the demand for organ donations and transplants. This thesis investigates organ donation and transplantation within Canada, pinpoints the root causes of the system’s failures, and offers policy
CHAPTER ONE: INTRODUCTION

suggestions to remedy these problems. Due to its dismal performance, Saskatchewan is given more in-depth treatment and analysis.

This thesis begins by describing the Canadian system for organ and tissue donation and transplantation and analyzes the effectiveness of this system. This thesis posits that failures are not due to a lack of knowledge or technical ability, but are because of a lack of donor organs. It is difficult to find any literature, popular or academic, that mentions organ transplantation and donation (ODT) without at least a brief mention of the supply shortage. As Shemie et al. (2011) demonstrate, “the demand for transplantable organs far exceeds supply” (2085) in Canada. Despite this, using an extensive analysis of the Canadian Organ Replacement Register (CORR) data from the Canadian Institute for Health Information (CIHI), they concluded that “[t]here has been no overall improvement in donation performance in Canada over the past 15 years.”

An even more pessimistic view is echoed by Baer (1997) who asserts that a “growing gap between supply and demand” and that “Canada’s organ shortage is severe and getting worse” (180). Her arguments stem principally from the fact that fewer and fewer in-hospital deaths are meeting the criteria required to make those patients organ donor candidates.

The David Foster Foundation states, “[t]here is a chronic shortage of most organs needed for transplant in Canada.” Lacroix, Mahoney, and Knoll (2004) specifically site the issue as supply, identifying “the organ donor shortage in Canada” (10). Laupacis et al. (1996) describe the problem as “a discrepancy between the donation rate and size of the waiting list” (241).
CHAPTER ONE: INTRODUCTION

While the experts in the field all agree there is a problem, the solutions they propose are inadequate or incomplete. Most of the propose policy solutions reflect a typically physician-centric philosophy. For example, Shemie et al. (2006a) builds recommendations around establishing protocols for classifying “deceased” and is thus who is eligible to be a donor. Their work also provides suggestions on how best to standardize practices for the timeliest removal of organs (Bernat 2010; Shemie et al. 2011).

Although these policy solutions have some merit, they all maintain a microscopic focus that does not consider systemic issues or non-medical perspectives. Often, even when the policy level is considered, the authors ignore implementation barriers. This is perhaps best exemplified by Klarenbach, Garg and Vlaicu (2006) who suggest creating a national regulatory body to reimburse donors for the expenses and losses they face from becoming donors. While the simple policy on the federal government removing the financial barriers of donation may be attractive, it ignores the fact that healthcare provision often occurs on a provincial basis and that national bodies are not well supported by provinces, which tend to view federal intervention or regulatory bodies as an infringement on their autonomy (Jordan 2009). It also fails to consider the profound ideological opposition to any further commodification of healthcare. Good policy not only considers the values, concerns, and incentives of all stakeholders but must also be placed in the appropriate constitutional, political and fiscal context.
CHAPTER ONE: INTRODUCTION

The goal of this thesis is to provide more realistically implementable solutions for Canada. It sets out to:

1. Perform an evidence-based analysis of the problem, including regional variations;
2. Set out policy options in terms of operating principles; and
3. Select among the options recommendations of broad policy solutions that will be consistent with the predominant value base in Canada but still deliver significantly better outcomes

How does organ transplantation work?

Organ transplantation has been attempted for centuries of human history. In eighth century BCE in China, where Pien Chi’ao was said to have cross-transplanted hearts in two patients to achieve balance in their personalities and in 3rd century CE where the Christian Saints Cosmas and Dimian were said to have replaced a gangrenous leg with that of a recently deceased Ethiopian (Lock 2002). Autographic skin transplantation—taking healthy skin from a patient and transplanting it to replace and repair damaged tissue—has been reported as far back as 2nd century BCE by Indian surgeon Suhruta, which is a more likely the first successful transplantation given the minimal rejection risk. Much later, in the 16th century, Gasparo Tagliacozzi, an Italian surgeon, did repeated autographic skin transplants but documented his failures in allographic skin transplants, where the source tissue comes from a donor rather than the patient themselves (Lock 2002). However, a limited understanding of the biological
mechanics of cells limited significant development in the field occurred until the middle of the 20th century.

Although Czech scientist Eduard Zirm successfully performed a transplant in 1902 of a human cornea, the identification of the immune reactions associated with transplant rejections in 1951 by Dr. Peter Medawar finally facilitated real organ transplantation progress. The first major organ transplants were made in the wake of that discovery: kidneys in 1954 by Drs. Hartwell Harrison and Joseph Murray, liver in 1967 by Dr. Thomas Starzl, and hearts in 1967 by Dr. Christian Barnard (Lock 2002).

From a medical perspective, the two major concerns with organ donation and transplantation are viability and rejection. Most organs rapidly deteriorate post-mortem, so, to prevent decay, there is an impetus to quickly identify potential donors. Immunosuppressive drugs and specific serotyping (matching of characteristics the immune system of the body uses to distinguish between ‘self’ and ‘non-self’ organisms) between the donor and recipient are now used to minimize the body’s natural rejection of foreign tissues and organs.

There are two primary sources of donor organs and tissues: live-donor and deceased-donor. Donation after cardiocirculatory death (DCD) and donation after neurologically determined death (NDD) further distinguish deceased-donor tissue. DCD is when a patient suffers from a non-recoverable injury and death arises from a cessation of all heart function (Shemie et al. 2006). NDD occurs when a patient meets all criteria to assume the irreversible loss of capacity for consciousness associated with the irreversible loss of brainstem function (TGLN
CHAPTER ONE: INTRODUCTION

2010). NDD is typically caused by brain injuries, either acute trauma such as stroke or head injury, or chronic such as central nervous system infections and encephalopathy (TGLN 2010).

In Canada, the consensus definitions for these types of death and their suitability for organ donation were taken from a consensus conference organized and coordinated in 2003 by the now defunct Canadian Council for Donation and Transplantation (CCDT). Once declared dead a patient can be screened for potential donor suitability. If there is an acceptable candidate and the appropriate permissions have been granted, the patient will be removed from life support and the organs and tissues are removed and stored for future transplantation. Table 1.1 shows the organs and tissues transplanted in Canada and their potential source donors.
# CHAPTER ONE: INTRODUCTION

## Table 1.1: Organs and Tissues Transplanted in Canada

<table>
<thead>
<tr>
<th></th>
<th>Thoracic Organs</th>
<th>Abdominal Organs</th>
<th>Tissues</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Organ</strong></td>
<td><strong>Potential Donors</strong></td>
<td><strong>Potential Donors</strong></td>
<td><strong>Potential Donors</strong></td>
</tr>
<tr>
<td>Heart</td>
<td>Deceased-donor</td>
<td>Deceased-donor or living-donor</td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Lung, complete</td>
<td>Deceased-donor</td>
<td>Deceased-donor or living-donor</td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Lung, lobe</td>
<td>Deceased-donor or living-donor</td>
<td>Deceased-donor or living-donor</td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td><strong>Abdominal Organs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Liver, complete</td>
<td>Deceased-donor</td>
<td></td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Liver, partial</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Deceased-donor</td>
<td></td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td>Bowel, segment</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td>Deceased-donor or autograph</td>
</tr>
<tr>
<td><strong>Tissues</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand/limb</td>
<td>Deceased-donor or autograph</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cornea</td>
<td>Deceased-donor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin</td>
<td>Deceased-donor or autograph</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Islet Cells</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Islets of Langerhans)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone marrow</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood (plasma, platelets or whole blood)</td>
<td>Living-donor or autograph</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood vessels</td>
<td>Deceased-donor or autograph</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart valve</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone</td>
<td>Deceased-donor or living-donor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: CCDT, 2006
CHAPTER ONE: INTRODUCTION

It is important to note that islet cells and corneas are defined as organ and tissue donations whereas hand/limb, skin, blood vessels and heart valves are all considered medical procedures rather than transplants. However, cornea data – unlike data for islet cells – are not available at the pan-Canadian level, and thus cannot be included in this study.

Blood and bone marrow are tissues and thus appear under the umbrella of organ donation and transplantation (ODT). However, in practice, they are distinct from the rest of the ODT system. Since blood and bone marrow are handled by the Canadian Blood Services and Héma-Québec, they operate in a manner very different from other organ and tissue donation organizations. Given this division of responsibility between pan-Canadian organizations for tissues and provincial organizations for solid organs and due to the inherent differences between tissues and thoracic organs and abdominal organs (the system for organs is far more complex and organs do not regenerate in donors like donated tissues), tissue donation and transplantation will not be part of this analysis.

Section 92 of the British North America (BNA) Act, which is included in the Constitution Act of 1982, states that hospital management is the exclusively provincial domain (Leeson 2004). As organ donation and transplantation only occurs in hospitals, it falls under provincial jurisdiction. However, as is the case with much of healthcare, it is too simple to assume that it happens in a vacuum on a province-by-province basis. Nine provinces maintain their own organ procurement organization (OPO)—bodies that match potential donors and
CHAPTER ONE: INTRODUCTION

recipients and generally oversee transplantations within their jurisdiction. There are 10 active OPOs in Canada, listed as follows (CORR 2011):

- Organ Procurement and Exchange of Newfoundland and Labrador (OPEN) – St John’s, NFLD
- Multi-Organ Transplant Program – Halifax, NS
- New Brunswick Organ and Tissue Procurement Program – Fredericton, NB
- Québec-Transplant – Québec, QC & Montréal, QC
- Trillium Gift of Life Network – Toronto, ON
- Transplant Manitoba: Gift of Life Program – Winnipeg, MB
- The Saskatchewan Transplant Program – Regina, SK & Saskatoon, SK
- Southern Alberta Organ and Tissue Donation Program (SAOTDP) – Calgary, AB
- HOPE Program – Edmonton, AB
- BC Transplant Society – Vancouver, BC

Four smaller jurisdictions: Prince Edward Island and the three northern territories of Yukon, the North-West Territories and Nunavut do not have any OPOs. Table 1.2 summarizes the availability of organ transplantation procedures performed in Canadian hospitals.
Table 1.2: Organ Transplantation Service by Hospital Location

<table>
<thead>
<tr>
<th>Province</th>
<th>City</th>
<th>Hospital</th>
<th>Kidney</th>
<th>Liver</th>
<th>Pancreas</th>
<th>Bowel</th>
<th>Islet Cell</th>
<th>Heart</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Columbia</td>
<td>Vancouver</td>
<td>BC Children’s Hospital</td>
<td>X</td>
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<tr>
<td></td>
<td></td>
<td>St. Paul’s Hospital</td>
<td>X</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Vancouver General Hospital</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Alberta</td>
<td>Calgary</td>
<td>Alberta Children’s Hospital</td>
<td>X</td>
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<tr>
<td></td>
<td></td>
<td>Foothills Medical Centre</td>
<td>X</td>
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<tr>
<td></td>
<td>Edmonton</td>
<td>University of Alberta Hospital</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
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<tr>
<td>Saskatchewan</td>
<td>Saskatoon</td>
<td>St. Paul’s Hospital</td>
<td>X</td>
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<tr>
<td>Manitoba</td>
<td>Winnipeg</td>
<td>Health Sciences Centre</td>
<td>X</td>
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<tr>
<td></td>
<td></td>
<td>Children’s Hospital of Winnipeg</td>
<td>X</td>
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<tr>
<td>Ontario</td>
<td>London</td>
<td>London Health Sciences Centre, Children’s Hospital</td>
<td>X</td>
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<td>London Health Sciences</td>
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<tr>
<td>City</td>
<td>Hospital Name</td>
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<tr>
<td>Hamilton</td>
<td>Centre, University Campus</td>
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<td>St. Joseph’s Health Care System</td>
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<tr>
<td></td>
<td>Hospital for Sick Children</td>
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<td>X</td>
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<tr>
<td></td>
<td>St. Michael’s Hospital</td>
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<tr>
<td></td>
<td>Toronto General Hospital (University Health Network)</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>Kingston</td>
<td>Kingston General Hospital</td>
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<tr>
<td>Ottawa</td>
<td>Ottawa Hospital</td>
<td>X</td>
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<tr>
<td></td>
<td>University of Ottawa Heart Institute</td>
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<tr>
<td>Québec</td>
<td>Montréal</td>
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CHAPTER ONE: INTRODUCTION

Table 1.2 shows clear gaps in service provision across the provinces. The Atlantic Provinces only have Halifax hospitals performing procedures. Certain procedures only take place in select provinces, such as bowel replacement which are performed only in Alberta and Ontario. Moreover, Saskatchewan has only one service provider performing a single service: kidney transplantation. By virtue of inter-provincial agreements, other services required by a resident of a province where it is not provided can be fulfilled in another where it is. There can be considerable specialization by hospital; for example, Toronto’s Hospital for Sick Children perform the majority of common paediatric transplants in Canada.

Is there a difference between NDD and DCD?

Two primary acceptable death criteria for organ donation candidacy create many of the ethical issues around ODT. For this reason, before discussing their repercussions in later chapters, it is important to define and better understand these criteria.

For decades, the only source of potential organ donors in Canada came from patients declared “brain dead”, that is to say, that met the NDD criteria. CCDT recognized the need to for a greater supply of organs and began establishing protocols for retrieving organs from patients who had suffered from cardiocirculatory death. The first step was a February 2005 forum called “Donation after Cardiocirculatory Death,” the third in a series designed to build best practices and ethical frameworks around the retrieval of organs and screening of potential donors (Downie et al. 2009). The Forum was a multi-
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disciplinary meeting with a wide-ranging, but specific set of goals. The Forum set the standard for Canadian ethical donation and retrieval practices. The Forum’s goals, summarized in Table 1.3, are pivotal to understanding what were considered acceptable to key Canadian stakeholders as of 2005.
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Table 1.3: Mandate of the “Donation after Cardiocirculatory Death” Forum

<table>
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<tr>
<th>Within the Mandate</th>
<th>Excluded from the Mandate</th>
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<tr>
<td>• Establish Canadian medical criteria for defining eligibility for organ donation after cardiocirculatory death</td>
<td>• Ethical considerations related to existing medical practice did not include the ethical framework for:</td>
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<tr>
<td>• Discuss conditions under which cardiocirculatory death, once anticipated or established, can activate organ donation procedures</td>
<td>i. Withdrawal of life-sustaining therapy (WLST) in the ICU: the medical decision to withdraw life support is within the domain of critical care practice. Discussion of these processes was limited to the manner in which they influence organ donation practice and organ viability</td>
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<tr>
<td>• Explore the ethical implications of DCD including:</td>
<td>ii. Not initiating or terminating cardiopulmonary resuscitation (CPR)</td>
</tr>
<tr>
<td>i. Defining death independent of the needs of organ donation and transplantation</td>
<td>• Ethnocultural and religious considerations regarding the cardiocirculatory determination of death from the perspectives of various communities</td>
</tr>
<tr>
<td>ii. Interventions on patients before expressed or granted consent</td>
<td>• Details of ex situ organ preservation</td>
</tr>
<tr>
<td>iii. Interventions after consent</td>
<td>• Issues related to organ allocation</td>
</tr>
<tr>
<td>iv. Potential conflicts of interest</td>
<td></td>
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<tr>
<td>v. Protecting and serving the public.</td>
<td></td>
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<tr>
<td>• Address consent issues (e.g., related to timing and accountability for decision-making)</td>
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<tr>
<td>• Define the technical procedures and preservation techniques for organ donation and procurement</td>
<td></td>
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<tr>
<td>• Define reasonable time limits for solid organ donation to be successful, including discussion of evolving techniques to maximize the opportunity</td>
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Source: Shemie et al., 2006 and CCDT, 2008
CHAPTER ONE: INTRODUCTION

The Forum developed certain condition-specific patient recommendations for the use of DCD, based on core ethical principles and a standardized terminology. The Forum considered all potential DCD to come from patients within two mutually exclusive and exhaustive conditions: controlled and uncontrolled. Controlled DCD occurs when death is expected, but has not occurred, which contrasts with uncontrolled where death has occurred, but was not anticipated (Shemie et al. 2006). The key consideration of the report is that at least two physicians, one of whom must be licensed in the relevant jurisdiction, are needed to declare DCD, based on a five-minute observation period†.

The five-minute observation period, however, brings certain legal ambiguities that further complicate DCD. According to Downie et al. (2009), there is no reason to believe that the five-minute period is a standard accepted practice, despite what the forum report asserts. Many western world practice standards seen in the 1997 Institute of Medicine Report on NHBD “also recommended a 5-min[ute] waiting period; the Pittsburgh Protocol requires 2 min[ute]; the First International Conference on Non-Heart-Beating Donors recommended 10 min[ute]; and Swedish law requires that a 20-min[ute] period of asystole elapse before death is declared” (Downie et al. 2009, 856).

†Due to the precise and clinical nature of this 5-minute period, the consideration is presented here, in its entirety: “The purpose of the 5-minute observation period is to confirm the irreversibility of cardiocirculatory arrest before organ procurement; Blood pressure is defined as an arterial pressure that generates anterograde circulation. The preferred method to confirm the absence of blood pressure is by arterial line monitoring.” (Shemie et al., 2006)
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Even though Canada approved DCD in 2006, only 264 DCD transplants occurred by the end of 2010 (CIHI 2010). The vast majority of these DCD transplants were in Ontario, the remainder essentially in Quebec. Hospitals in Alberta began performing DCD transplants in 2009, but have only performed four thus far. British Columbia and Nova Scotia began in 2010, but have only performed two each. DCD accounted for only 10 percent of deceased organ and tissue donations in Canada in 2010, so it is not nearly providing the intended boost to organ supply. The lack of clear, cohesive standards is a likely barrier, particularly when calls for the type of process and standard building done at the first two CCDT fora for NDD dominate the physician literature around the topic (Doig 2006; Phua et al. 2007; Gill et al. 2008; Childress 2008 for example).

Additionally, case evidence suggests that the five-minute period does not confirm irreversibility, as resuscitation has been shown effective after as long as 20 minutes after the cessation of cardiocirculatory arrest (Valenzuela et al., 1997; Adhiyaman et al. 2007). Even supporters of the suggested protocols acknowledge that medical evidence supporting irreversibility after five minutes is, at best, “modest” (Bernat 2006). The studies rely on patient observation data collected in the 1960s and 1970s (Downie et al. 2009). The ideal situation would be to run properly controlled and powered tests, but that is nearly impossible due to the obvious ethical constraints around forgoing medical treatment. Thus there is ambiguity for hospitals, which may not choose the standards presented by the CCDT and instead may choose alternate times or, worse, find the legal risk and
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judgments required—due to no clear standard—too daunting and may opt to ignore DCD altogether.

*How does Canada perform?*

International standing is a simple metric by which to gauge the relative efficacy of the Canadian system. The articles discussed so far make exclusive reference to the problems being fundamental issues of supply. The literature makes no mention of failures in infrastructure in Canada, nor is there any mention of failures in health human resources – capacity, training, skill or otherwise. Even if the issue were a disproportionately high burden of end-stage organ failure in Canada, the issue would still be the shortfall of supply to meet that increased burden. Thus, the number of donors is the first measure to consider. Figure 1.1 shows an international ranking of organ donors, standardized per million, for all organs donated in 2009.
Figure 1.1: International Comparison of Organ Donors

Source: Sheehy et al., 2003; European Commission, 2010, RODaT, 2011
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In terms of the critical metric of the number of donors per capita, Canada is a poor performer relative to most advanced industrial countries, and is only slightly above the poorest country performers including the United Kingdom, the Netherlands, Australia, Denmark and New Zealand. As Canadians take great pride in the quality of, and access to, their health system, this result warrants deeper investigation. What will likely be the most surprising to Canadians is that Canada ranks far behind the United States, a country that Canada usually surpasses on most health system indicator rankings, especially on access indicators.

Why transplantation?

In the case of organ/tissue failure, mortality is almost certain without transplantation (Knaus et al., 1985). The one exception is kidneys, an interesting outlier in the end-stage organ failure spectrum. Renal replacement therapy can lower the mortality rates of end-stage renal failure, specifically stage 5 chronic kidney disease (National Kidney Foundation 2002). Renal replacement therapy comes in two forms: kidney transplants or dialysis. Of the two, many regard kidney transplantations as the superior option, in terms of improved quality of life at a reasonable cost, based upon a quality-adjusted life years (QALY) measure (Garner and Dardis 1987 and Karlberg and Nyberg, 1995, Howard et al. 2009). Dialysis is an expensive course of treatment, especially when compared to the transplantation’s one-time surgery expenditure followed by much less expensive immunosuppressant drugs (Laupacis et al., 1996). Moreover, the dialysis is so involving and exhausting for patients that they normally are unable to work while
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undergoing treatment. The benefits of transplant also include improved patient productivity. Such improved outcomes not only mean further financial advantage from the tax revenues of the worker, but also from the patient quality of life and autonomy improvements.

Laupacis et al. (1996) shows that renal transplantation leads to not only reduced costs in treatment of end-stage renal disease, but universally improved quality of life outcomes regardless of age, sex, or co-morbidities. This research shows that regardless of the circumstances surrounding a transplant, a patient should show improvements in their QALYs, a measure of life expectancy adjusted for quality of life. Renal transplantation manages to not only improve patient outcomes but do so at a lower cost to the system. Ultimately, transplants are a net benefit to the system. The next step is to examine the policies that impact organ donation and transplantation and to assess the potential operating principles Canada could operate under.
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The operating principle of ODT in Canada

Organ donation, like most of healthcare in Canada, is subject to an array of federal-provincial programs, funding, legislation and policy. In 1999, *Organ and Tissue Donation and Transplantation: A Canadian Approach*, released in April by the Standing Committee on Health for the House of Commons and *A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada* was released in November by the National Coordinating Committee on Organ and Tissue Donation, Distribution and Transplantation (NCC). Both reports called federal attention to the perceived need for a “framework for a coordinated and comprehensive donation and transplant strategy proposed by the National Coordinating Committee is based on current evidence and best practices” (NCC 1999). The federal government accepted the reports’ findings “as the framework for discussions with the provinces and territories towards the establishment of a sustainable solution for transplantation in Canada” (Health Canada 1999). This set the stage for the April 2001 creation of the Canadian Council for Donation and Transplantation (CCDT). The CCDT had the following mandate (Norris 2009):

- a coordinated pan-Canadian strategy and high-quality provincial/territorial strategies;
- standards and clinical practice guidelines based on leading/best practices;
- social marketing strategies and their implementation;
- pan-Canadian information management systems;
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- educational resources for interdisciplinary professionals involved in donation and transplantation processes;
- a system to monitor the performance of the Canadian experience against the experience in other jurisdictions and progress towards implementation targets; and
- an ongoing process to identify emerging issues and link to the strategic process.

Originally a Secretariat of Health Canada, in 2004 the CCDT was re-established as an arm’s length non-profit which received funding from Health Canada. CCDT failed its mandate by focusing solely on making recommendations about standards and clinical practice guidelines on determination of death (cardiac death and brain injury) and immunological risk faced by patients post-transplant. The CCDT spent extensive time on consultations at the expense of its other mandated items, particularly social marketing and public awareness, “whose importance was emphasized in the two reports” which were the basis for establishing the organization (Norris 2009).

Although the CCGT’s work is extremely valuable, the lack of marketing and public awareness campaigns damaged the CCDT politically. In 2008, under the umbrella of the Canadian Blood Services (CBS), the CCDT became the Organ & Tissue Donation and Transplantation (OTDT) (CBS 2008). This shift poses significant challenges to the mandate as it no longer functions nationally, as
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

Québec operates its own blood and tissue services agency (Héma-Québec). The result is that the OTDT provides only the most basic services to provincial OPOs.

The OTDT currently runs the Living Donor Paired Exchange (LDPE) Registry, an online database of two types of living renal donors. Incompatible donor-recipient pairs are individuals with end-stage renal disease and a willing kidney donor who are not biological matches, while non-directed donors are willing kidney donors who simply wish to donate to anyone in need. Every three months, the LDPE Registry is updated and an algorithm attempts to match donors and recipients (OTDT 2012). The result is three principal outcomes for successful matching: paired exchange, N-Way exchange, and domino exchange. Paired exchange is when the LDPE Registry can successfully match 2 or more incompatible donor-recipient pairs. Two pairs work as a simple crisscross exchange, which appears in the Figures 2.1 and 2.2.
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Figure 2.1: Paired Exchange
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Figure 2.2: N-Way Exchange
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The N-Way exchange is when there are more than two incompatible donor-recipient pairs, where the donor provides a kidney to each successive recipient, and the final donor donates to the first recipient. A domino transfer occurs when a non-directed donor enters the system. The non-directed donor then initiates an N-Way exchange that ends with the final donor instead being matched with a waiting transplant patient from the non-directed donor’s home jurisdiction. The domino namesake comes from the chain reaction the non-directed donor sets in motion.
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Figure 2.3: Domino Exchange
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The OTDT also manages the National Organ Waitlist (NOW), planned to launch in early 2012 (OTDT 2012), which will be a Canada-wide, excluding Québec, registry of all patients with end-stage organ failure awaiting transplant, with the exception of end-stage renal failure. Its goal is to “be used for inter-provincial sharing of organs” (OTDT 2012).

The third and final registry run by the OTDT is the Highly Sensitized Patient (HSP) Registry for end-stage renal patients awaiting transplant who have developed Human Leukocyte Antigens (HLA) through pregnancy, previous transplants or blood transfusions, and have increased difficulty in obtaining a match. Also planned for introduction in 2012, the HSP Registry is anticipated to provide “tools to support offering of organs and tracking of inter-provincial organ sharing” and “a virtual crossmatch [which] will also be available for assessing potential heart, lung and pancreas matches” (OTDT 2012).

Although the OTDT attempts to be a national service provider and coordinator for Canadian organ and tissue transplantation and donation, the majority of the system is funded, administrated and regulated at the provincial level. Provinces manage their own Organ Procurement Organizations (OPOs), sometimes in co-operation with other provinces and territories, and they are responsible for retrieving, matching, coordinating, and transplanting organs and tissues within their jurisdiction. The provinces are responsible for identifying their donor pool and assessing their potential donors.
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The Canadian organ and tissue donation system assumes that no one is a voluntary organ and tissue donor by default. If an individual wishes to have his or her organs assessed for donation post mortem, they must self-identify. Most provinces’ systems default to the next of kin’s decision as a matter of practice. Yet, in theory, a self-selection mechanism, such as an organ donor card or the orange sticker affixed to the health card, is sufficient. For this reason, this type of system is an “opt-in” system – what will be referred to throughout this thesis, a “requested consent” operating principle.

Three operating principles

Three alternative operating principles will be compared and contrasted with the requested consent operating principle relied upon in Canada. The first is the presumed consent operating principle, which contrasts directly with the requested consent operating principle – the operating principle used currently in Canada. These are the two fundamental characteristics of all organ and tissue donation and transplantation systems. These principles are mutually exclusive, meaning that any formal program can belong to one and only one of those categories.

The next two operating principles, the reciprocal altruism operating principle and the legitimate market-based operating principle, are variations that, while only seen under requested consent operating principles in practice, have no characteristics that prohibit them from operating in concert with the presumed consent operating principles. These variations were chosen only
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

because they are the only alternative models currently in use. Although there is a
great deal of variation between the actual policies and procedures of jurisdictions,
the fundamental description of their systems can be described as either presumed
consent or requested consent. They may vary in their sources of cadaver
donations, such as their acceptance of NDD and DCD or their practices for
compiling citizens’ preferences for participating in the ODT system, but a key
descriptor is always a function of their legislation of consent.

This categorization method is similar to the healthcare systems of
individual Canada provinces and American states. They have many individual
differences; from the types of treatments and practices that are publicly covered
to their regulatory frameworks. However, fundamentally, they fit into one of two
groups: single payer government insured healthcare (all Canadian provinces) or
privately insured healthcare with public insurance for the poor and the elderly
(all American states). The reciprocal altruism operating principle and the
legitimate market-based operating principle are innovative differentiations from
the requested consent operating principle. They alter the incentives and
behaviours around ODT sufficiently that for the purposes of this thesis they are
considered as separate operating principles.

The presumed consent operating principle is used by various Western
European nations. The reciprocal altruism operating principle is now the
dominant approach in Israel, while the legitimate market-based operating
principle is restricted to Iran. The last two models are unique to those respective
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nations. The models will be assessed for how effective and efficient they are at improving the supply shortage and generating fiscal outcomes. The models will also be examined from political and ethical standpoints, as well as their political and policy viability within the Canadian context.

Another option is the mandatory consent operating principle. Mandatory consent operating principles consider all individuals as potential organ donors post-mortem, regardless of their preferences or beliefs. While this model is not in use anywhere in the world, proponents exist, particularly in the popular media, as with Carney (2008). It is an important topic and an interesting—though often controversial and divisive—idea. However, given that at the current time it is such a radical departure from existing policies, with no evidence of consideration for adoption in any jurisdiction anywhere, this thesis will only touch on the mandatory consent operating principle. It will not be considered as a potential alternative operating principle.

The presumed consent operating principle

In terms of consent, many Western European jurisdictions assume the opposite of the requested consent operating principle. In jurisdictions operating under the presumed consent operating principle the default assumption is that legally dead individuals consent to having their organs considered for donation. As such, individuals must instead self-identify if they want to be removed from the system, typically by formally registering with the organ procurement organization. Thus, by contrast, this system is commonly known as “opt-out” or
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“presumed consent.” Table 2.1 provides an incomplete list of jurisdictions organized by their organ donation regime.
Table 2.1: Countries by Consent for Organ Donation

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<th>Jurisdictions with....</th>
<th>Requested Consent</th>
<th>Presumed Consent</th>
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<tr>
<td>Australia</td>
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CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

Note that although Canada and the United States appear as single jurisdictions in international comparisons, they both delegate their healthcare (and thus organ and tissue donation) systems to the provincial or state level. All provinces and states currently base their respective ODT systems on a requested consent operating principle, therefore both countries can be presented as requested consent jurisdictions.

Presumed consent operating principles attract significant attention in English-speaking countries as a potential solution to organ donor shortages, most of which operate under the principle of requested consent in their approaches to organ and tissue shortages. Behavioural economics predicts that the simple policy shift should result in a larger supply of donors due to basic inertia. The underlying assumption is that there are people who are in favour of being donors, but assign a small benefit to it. Providing consent or registering as a donor is not without cost: there are forms to fill out, next of kin to inform and the psychological difficulty of considering one’s mortality. Therefore, for a non-trivial number of individuals, the benefit is smaller than the cost of opting in; individuals who wish to be organ donors do not self-include due to the inconvenience and time costs to do so. By switching to a presumed consent system, becoming a donor is costless. Thus no willing donor is excluded from the system. This inversion, however, creates a cost for the individuals who are unwilling to become organ donors, a tradeoff that is discussed more thoroughly in Chapter Three. It is important to note that while diametrically opposed, both required and presumed consent operating principles allow for individual choice.
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The presumed consent operating principle is well understood in Canada. It is discussed as a policy option for Canada frequently in the media. Most newspapers, major television networks and even Maclean’s magazine have all run articles about the proposition of adopting the presumed consent operating principle. The presumed consent operating principle has long been championed by the literature in Canada (Moustarah 1998; Canadian Liver Foundation 2010). The presumed consent operating principle is to widely known to not be part of any discussion about improving the ODT system in Canada.

The reciprocal altruism operating principle

The reciprocal altruism operating principle is an attempt to solve the organ and tissue donation “free rider” problem—a term used in economics, psychology and political science for the situation when someone consumes a resource without making a full contribution to the owner of the resource in respect to its cost or value. The name comes from a classic example, where a city bus makes scheduled stops around an area and a rider does not pay the fare, but still receives the service, increasing the burden on the riders who do pay. The analogy is that organs and tissues are in short supply, so those who would receive organs when in need, but who do not contribute their own are the free riders. They exacerbate demand without increasing supply.

The reciprocal altruism operating principle attempts to link participation with drawing value from the system more closely—the willingness to donate organs and tissues to determine an individual’s eligibility as a recipient. The
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benefit from being willing to participate in the organ donation system could range anywhere from a prioritization in the transplantation queue to being used as a gate-keeper to allow access to transplantation generally.

Israel is the only jurisdiction in the world that currently uses a reciprocal altruism operating principle. Before adopting their current system Israel’s organ and tissue donation system was based on the requested consent operating principle and looked similar in some respects to that of any Canadian province. They had organ donor cards signed by would-be donors. However, ultimately, it was the decision of the next of kin whether or not an individual could be considered as a donor after brain-death had been determined (Lavee et al. 2010). Not satisfied with this system, the Israeli government implemented a new system based on reciprocal altruism beginning in January of 2010 (Brunner 2009). A key amendment to the existing organ transplantation laws now allows Israeli OPOs to prioritize patients with end-stage organ failure in the queue for donor organs if they, or their first-degree relatives, have signed organ donor cards for over three years or have been post-mortem or non-designated living organ donors† (Lavee et al. 2010).

In the first year of this new system, everyone with signed organ donor card received the priority status after a one-year waiting period. The system was based on the recommendations of the Israel National Transplant Council’s

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† Non-designated living donation is when a live donation is made not for a specific individual (such as a family member, significant other or friend), but donated freely to be used by the system as it sees fit. Directed living donation, by contrast, is donation where the donor specifies an intended recipient.
special interdisciplinary committee that met in March 2006. Yet, the INTC recommended that directed living donation be included as a condition for prioritization, and is appealing the Israeli Parliament to reconsider.

In Israel medical evidence remains the primary determinant of queue placement of patients requiring transplantation. Any candidate under the age of 18, having a mental disability or otherwise legally unable to opt into the organ donation system, will still have priority status for organ allocation. Israel uses a scoring tool specific to each organ to assess where a candidate will be placed in the queue. For respiratory failure, there is a lung allocation score (LAS) on a scale from 0 to 100. Based on a variety of variables and patient characteristics, an algorithm calculates the projected 1-year survival time without a transplant and the probability of rejection and failure during the 1st year of transplant and determines this score.

For hepatic failure, the model for end-stage liver disease (MELD) is on a scale from 6 to 40. A patient’s blood measurements of creatinine, bilirubin, and an international normalized ratio help calculate this score. For renal failure, an allocation score ranging from 0 to 18 assesses the severity of the failure. The candidate’s age, the amount of time the candidate has spent in the queue, their panel-reactive antibody concentration, and the degree to which their Human Leukocyte Antigens (HLA) match with the prospective donor comprises this score for priority on the waitlist for kidneys.
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There is no score for cardiac failure. Instead, organ transplant recipient candidates are categorized by heart function. Status 1A and 1B is the most severe, where patients are dependent on mechanical circulatory support, continuous mechanical ventilation, or continuous high-dose intravenous inotrope infusion (Lavee et al. 2010). Candidates who have category 1A end-stage cardiac failure, LAS scores greater than 70 (or who otherwise must be ventilated) or MELD scores greater than 30, are given priority allocation regardless of their eligibility given the new system. In cases where two or more candidates are equally suitable for a donated organ, prioritization under the new regime will break the tie. Table 2.2 is a breakdown of the scoring benefits under the new system.

The reciprocal altruism operating principle is a new concept to ODT, and not very well understood in Canada. Given that it has only recently come into effect in Israel, most attention is on how it will impact their ODT system rather than suggestions it be implemented in Canada. Due to its emphasis on equivalence and the interesting ethical and legal challenges it brings with it, it is an important system to evaluate. Radical ideas may hold the key to improving Canada’s poor ODT performance and regardless of whether or not reciprocal altruism is a good fit; it will be interesting to assess such a radical departure from the current landscape of ODT operating principles.
Table 2.2: Israeli Additional Allocation Prioritization Scoring

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<tr>
<th></th>
<th>Kidney (Score)</th>
<th>Lung (LAS)</th>
<th>Heart (Status)</th>
<th>Liver (MELD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candidate has a signed donor card</td>
<td>2</td>
<td>10</td>
<td>Top of Status 2 list (behind Category 3 candidates)</td>
<td>2</td>
</tr>
<tr>
<td>Candidate has a first-degree relative who has a signed donor card</td>
<td>1</td>
<td>5</td>
<td>Top of Status 2 list (behind Category 1 candidates)</td>
<td>1</td>
</tr>
<tr>
<td>Candidate has a first-degree relative who was an organ donor (post-mortem or non-designated living)</td>
<td>3.5</td>
<td>15</td>
<td>Top of Status 2 list</td>
<td>3.5</td>
</tr>
</tbody>
</table>

Source: Lavee et al., 2010
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

The legitimate market-based operating principle

The legitimate market-based operating principle reveals one of the greatest global challenges facing organ donation: the black market sale of and commoditization of organs and tissue. Organs and tissues are scarce resources with few substitutes. Basic economic theory says these characteristics make them valuable. The demand is so great that kidneys and livers regularly fetch as much as $150,000-$160,000 USD (Suddath and Altman 2009; Khatib 2009). High prices provide a greater incentive to do drastic things to bring a product to market. Criminal enterprises selling organs acquired through duplicitous means such as paying less than the promised fee to the desperate donor, not paying at all, or acquiring the organs by force are prevalent in India and Pakistan (Srinivasan 2008).

Estimate say between 5 to 10 percent of worldwide kidney transplants in any given year involve illegal organ trafficking (Budiani-Saberi & Delmonico 2008). In 1994, Guatemala had an epidemic of riots and attacks on foreigners stemming from rumours of baby snatching for the purposes of organ removal for sale abroad (Adams, 1998). In 2007, Canadian MP David Kilgour wrote a report on accusations of Chinese organ harvesting from unwilling prisoners, particularly from practitioners of Falun Gong. He concluded “[b]ased on our further research... the allegations are true. We believe that there has been and continues today to be large scale organ seizures from unwilling Falun Gong practitioners” (Kilgour and Matas 2007). In December of 2010, the Associated Press reported that in Kosovo “[a] t least nine people, including a former senior Health Ministry
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

official, are suspected of involvement in an international network that falsely promised poor people payment for their kidneys, then sold the organs for as much as €100,000 ($137,000).” In 2010 Netcare, South Africa’s largest private healthcare firm, admitted that its executives were working with South African and Israeli physicians to acquire kidneys to sell on the black market (Kockett 2010).

The practice seems to be pervasive worldwide, with physicians, executives and government officials participating. This quote from Dr. Gabriel Danovitch, a transplant specialist at UCLA’s David Geffen School of Medicine sums it up best: “To some extent... there are vested interests, there is money to be made" (Associated Press 2009). Given the pervasiveness of illegal organ trade, it is not surprising that the legitimate market-based operating principle has attempted to solve organ shortages by legalizing and attempting to regulate the market. Under the legitimate market-based operating principle the jurisdiction can set out terms in attempt to curb the illicit behavior and regulate an acceptable standard for ethical sale of organs.

The Iranian legitimate market-based operating principle differs greatly from the Canadian model. In fact, Iran is the only jurisdiction where the sale of organs for living-donor organ donation is legal. Figure 2.4 shows the sources of kidney donation for the period of 1984 to 2000.
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

Figure 2.3: Iran Renal Transplants by Source

Source: Ghods, 2002
CHAPTER TWO: THE OPERATING PRINCIPLES OF ODT

Whereas Canada’s organ supply comes almost entirely from deceased donation, Iran bases its renal transplantation program on living donation. An even greater contrast shows that more than three quarters of Iran’s donations are non-designated, while Canada’s living donations are almost exclusively directed.

Like many other non-Western countries there is strong distrust of cadaveric donation in Iran, as a result of cultural and religious issues. Consider Japan, which did not recognize brain death as a valid option for organ procurement until 1997 and, according to the Japan Organ Transplant Network (JOTN), is still met with a negative attitude and general apprehension. Similarly, Iran did not legally recognize brain death until April 2000 and has made few improvements in public perception, despite religious decrees (fatwas) endorsing it (Ghods 2002). By 2005, Iran performed 15,635 non-designated living renal transplants and 3,421 living-related transplants, but only 823 cadaveric-sourced kidney transplants (Ghods and Savaj 2006).

Iran began a modest renal transplantation program in 1967. By 1985, they performed no more than 100 kidney transplants (Ghods and Savaj 2006). When dialysis use and transplant waitlists rapidly increased, the government began sending patients abroad to receive transplants, principally to the United Kingdom. However costs soon proved prohibitive. Thus the government began to focus on living relative donation in 1985, establishing two teams who performed 274 transplants by 1987 (Ghods et al. 2000). By 1988 the teams proved too slow and the state introduced a policy to combat spiraling costs from end-stage renal
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disease and expensive dialysis treatment: the legal sale of kidneys. In 1999, Iran became the only jurisdiction without a waiting list for kidneys, which is still true today (Haghighi and Ghahramani 2006).

Iranian physicians promote living relatives as potential donors for end-stage renal failure patients and encourage patients undergoing evaluation to seek out any potential family member willing to donate a kidney. If the patient is unable to find a family source, they are referred to the Dialysis and Transplant Patients Association (DATPA), who operate the non-designate living donor-matching program (Ghods and Savaj 2006). Due to the aforementioned societal stigma against deceased donation, only the transplant unit at Shiraz University screens for deceased donor matches (Ghods and Mahdavi 2007). DATPA does not provide any incentive or reward for referral to a transplant team, who are strictly university hospital employees with public provision of all transplant related hospital expenses (Ghods and Savaj 2006). In return for their kidney, the donor gets an average of $1,200 USD, paid by the state, and $2,300 to $4,500 USD provided by the recipient (with contributions from various charitable organizations working with DATPA, which oversees the process dependent on the ability to pay). The donor also receives one year of state-provided medical coverage (Jha and Churgh 2006). The Iranian government also provides subsidized immunosuppressive drugs, typically cyclosporine neoral and mycophenolate mofetil (Ghods and Savaj 2006). Furthermore, renal transplant teams may not receive any compensation outside of their regular pay and only Iranian citizens may participate in the program (Ghods 2002).
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Many other nations have taken notice of Iran’s impressive results, seeing a solution to swarming in their expanding medical care costs as well as the undeniable fiscal efficiencies provided by renal transplantation. In fact, having legalized state payment for organs in 2009, Singapore has recently announced plans to pay up to 50,000 SGD (over $38,000 CAD) per kidney (Tabarrok 2010). Given the impressive results of the Iranian system and the traction the legitimate market-based operating principle is gaining in the rest of the world, it is imperative that it be assessed as a potential solution for Canada’s ODT crisis.
Given the strong connection to mortality, organ donation and transplantation involve significant ethical implications. The donor, for most organs, must be dead. Living donors put themselves at a greater risk of death, either directly from the procedure or indirectly from future complications. Whether or not a potential recipient receives a transplant is often a life or death matter and is always quality of life issue. Therefore, organ and tissue donation and transplantation (ODT) ethics are an essential discussion. Many of the most passionately held beliefs stem from personal beliefs about life and death, and create some of the most controversial debates (abortion, euthanasia, etc.). Thus, the ethics of any proposed change to the ODT system may be even more important than its efficacy at increasing the number of organ donors.

The ethical issues around organ procurement raise a larger ethical issue: the determination of death. The determination of death is the set of medical criteria by which an individual can legally, and philosophically in many cases, be considered deceased (Bernat et al. 2010). This is a relatively new issue in ethics as “[b]efore the development of modern critical care, the diagnosis of death was relatively straightforward: patients were dead when they were cold, blue, and stiff” (Truog and Miller 2008, 674). As modern medical technology became more proficient at not only resuscitating circulation and respiratory function, but also replacing them mechanically, the gap between ability and understanding became pronounced around the definition of death. More specifically, an individual could maintain cardiopulmonary function, but lack any neurological capability, particularly consciousness. First, however, it is necessary to understand what
scientists within the medical community mean by a lack of consciousness. This requires an understanding of disorders of consciousness, described in Table 3.1.
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#### Table 3.1: Disorders of Consciousness

<table>
<thead>
<tr>
<th></th>
<th>Patient Displays of</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Awareness</td>
<td>Sleep-Wake Cycles</td>
<td>Behaviour</td>
</tr>
<tr>
<td>Minimally Conscious State</td>
<td>Irregular displays</td>
<td>Present</td>
<td>Inconsistent displays</td>
</tr>
<tr>
<td></td>
<td>of awareness</td>
<td></td>
<td>of purposeful behaviour</td>
</tr>
<tr>
<td>Vegetative State</td>
<td>Absent</td>
<td>Present</td>
<td>Displays of reflexive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>or non-purposeful behaviour only</td>
</tr>
<tr>
<td>Chronic Coma</td>
<td>Absent</td>
<td>Absent</td>
<td>Displays of reflexive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>behaviour only</td>
</tr>
<tr>
<td>Brain Death</td>
<td>Absent</td>
<td>Absent</td>
<td>Absent</td>
</tr>
</tbody>
</table>

Source: Bernat (2006 & 2010), Seel et al., 2010
CHAPTER THREE: ETHICS

Vegetative states are further classified by duration. Once a patient is in a vegetative state for four weeks, they are in a persistent vegetative state. When a patient has been in a persistent vegetative state for longer than one year recovery is impossible according to currently understood medical knowledge (The Multi-Society Task Force on PVS 1994). For ODT purposes, it is important to differentiate brain death—commonly accepted as death for the purposes of organ procurement—from a vegetative state, which typically meets with political and legal controversy around a declaration of death and the withdrawal of life support (eg. Terri Shiavo, Karen Ann Quinlan, Tony Bland et cetera).

While Table 3.1 suggests that brain death is a clear-cut definition for deceased, the truth is much more complicated. Consider the following contrast between a living patient, a brain dead patient, and a cardiopulmonary deceased (heart dead) patient put forward by Truog and Robinson (2003), summarized in Table 3.2.
### Table 3.2: Patient Contrasts by Live-Death Status

<table>
<thead>
<tr>
<th>Features</th>
<th>Patient Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Living</td>
</tr>
<tr>
<td><strong>Blood circulating, warm, well perfused</strong></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Breathing</strong></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Capable of somatic growth and development</strong></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Capable of reproduction</strong></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Capacity for Consciousness</strong></td>
<td>Yes</td>
</tr>
</tbody>
</table>

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Truog and Robinson (2003) make a small caveat about breathing while brain dead: “With ventilator. Some might argue that it is the capacity to breathe spontaneously that is associated with life, yet quadriplegic patients are not regarded as any less “alive” just because their breathing is not spontaneous” (2392). As such, they conclude that the only distinction between living patients and brain dead patients is a lack of consciousness. However, as seen in Table 3.1, a lack of consciousness alone does not necessarily dictate death by medical, legal, or popular opinion.

The difference between brain death and other disorders of consciousness may be in a lack of an accurate understanding of the definition of brain death. Patients often spontaneously emergence from vegetative states: a 50 percent recovery rate in adults within the first 6 months (Jennett 2002). Patients in persistent vegetative states longer than one year have no recorded incidents of recovery (Plum 1999). Stories regularly appear in the media about such “miraculous” recoveries but after investigation they do little to disprove the previous figures (Cranford, 2004). The conceptualization of death for patients who are brain dead is not even consistent among the medical community, perhaps best exemplified by the ongoing debate between anaesthesiologists regarding the use of pain-numbing analgesics on NDD patients during organ procurement procedures (Young and Matta 2000; Poulton and Garfield 2000; Keep 2000; Wace and Kai 2000; Dagleish 2000).
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The discussion shows how imperfect understanding can obstruct the conversation around ODT. Physicians may disagree about the particulars, but it is generally accepted that NDD (brain death) is death. The confusion about states and disorders of consciousness among the general public prevents the discussion from reaching a wider audience. Not only does misunderstanding the concept of NDD prevent some individuals from consenting to be organ donors, it prevents them from contributing to the discussion. Ethical consent is informed consent, so all Canadians must have an adequate understanding of the fundamentals of ODT before they can agree to changes to the details. Regardless of whichever operating principle is chosen – even staying with requested consent – the government must do a better job on education around the concept of death as it is accepted by the medical community. Without that understanding the government cannot expect Canadians to participate in ODT, regardless of the operating principle.

Individual ethics and ODT in Canada

An ethical requirement for ODT is a clear distinction between who requests consent and who provides medical treatment. A principal concern about having the attending physician make the request for consent to organ donation from the next of kin is simply a matter of perception. Having the physician act as the agent for the OPO is distasteful for all involved. The physician may find it awkward and uncomfortable to be asking the next of kin immediately after announcing the patient died in their care. This may cause the physician to
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neglect the duties, avoid making requests, or simply not put much effort into the request.

It may be equally awkward for the next of kin. Organ donation is a particularly sensitive topic, to the extent where organizations like British Columbia Transplant have to include the following in their frequently asked questions (FAQ):

“Q: If I am a registered organ donor, will healthcare providers make every effort to save my life?” (Transplant.bc.ca, 2011)

If the OPOs still find it necessary to dispel the myth that the death of potential organ donors are viewed as positive, it is not effective policy to encourage the primary practitioners to be the requester for organ donation.

The mental health of the practitioner must be considered. The primary practitioner may currently be suffering from anguish due to having a patient die while under their care. Placing someone in a fragile state into an awkward position with one or more individuals in emotionally vulnerable positions who are processing the same terrible circumstances and may be emotionally vulnerable may cause strain and may result in outbursts or violence. To put anyone through those circumstances when alternatives are readily available is dangerous and negligent. Trained, independent requesters are clearly advantageous not only for the system itself, but for the potential donors, their next of kin, and all healthcare professionals involved. Independent requesters
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avoid these types of perception issues and are thus essential to an ethical operating principle.

Another important ethical concern with almost any medical technology or procedure is whether it violates an individual’s body rights. When considering the removal of organs in particular, policy makers need to consider the beliefs surrounding the body’s integrity, particularly post mortem. Religious belief is closely tied to these beliefs. The Appendix provides a summary of how the tenets and philosophies of the major religions of the world relate to organ donation. The Appendix illustrates how organ donation is a commonly accepted practice. Among most of the major religions, it is actively encouraged, with many prominent members and respected leaders speaking out in favour and pointing to religious citations from their respective holy texts for support. The most common practice among religious groups is that ultimately, the choice to donate is personal.

Taking into account the religious profile of Canada, the results are even more significant. According to the 2001 census, Canada was approximately 43.2 percent Catholic, 29.2 percent Protestant, 6.4 percent Other and 15.6 percent without religion. Since 1921, essentially every religious category has been declining, while the “without religion” category has been steadily increasing. Although the data is over a decade old, these trends have likely persisted. Only 1

5 The OPO of Ontario, Trillium Gift of Life Network, commissioned specific brochures showing the religious establishment’s encouragement of organ donation for Catholicism, Hinduism, Islam, and Judaism. For more detailed quotes and examples, as well as a breakdown of the official stance on ODT by religion, see Appendix A on page xx.
percent of Canadians identified as having “no religion” in 1971 with 23 percent
self-identifying as such “two generations later” (Valpy and Friesen 2010). Valpy
and Friessen (2010) describe Canada being on a “march towards secularization.”
It is reasonable to assume that the majority of non-religious individuals
(principally atheists and agnostics) have no major ethical concerns about what
happens with their body post-mortem and thus would not object to organ
donation.

In 2001, the three largest religious denominations (excluding no religion,
which is the third largest category) in Canada were Catholic, Protestant and
Muslim. All three religions are strong supporters of organ donation. Likewise, in
2001, the largest Protestant denominations in Canada—United Church of Canada
at 9.6 percent, Anglican at 6.9 percent and Baptist at 2.5 percent—favour organ
donation. Trends in immigration show non-religious as the fastest growing
religious group among new citizens, followed by Muslim, Hindu, and Sikh. All of
these groups also support organ donation. Thus it can be said that the religious
cclimate is accepting of organ transplantation and will likely only become more so.
Ultimately, the growing number of non-religious Canadians and the
overwhelming support of the majority of religions for organ donation suggests
minimal religious resistance to organ donation.

In Canada, the religions that have major ethical concerns with organ
transplantation—Confucianism, Shinto, Christian Science, and Jehovah’s
Witness—have relatively few observers. Jehovah’s Witnesses comprise less than 1
percent in 2001 and had been steadily dropping by thousands of members each decade, while the remaining three listed above are unlisted (Census data 2001).

However, two main gaps in the gathered data exist. The first area of concern is traditional Aboriginal religions for which there is little written information. However, even assuming that among declared practitioners of these religions there is universal rejection of organ donation, according to 2001 Census data, they are less than 0.2 percent. However, as most practitioners of Aboriginal religions would be on reserve and thus outside of the jurisdiction of provincial health policies, it is outside the scope of this thesis to discuss such implications.

The second area of concern is that religion is not monolithic. A subscriber to a particular faith does not necessarily ascribe to every tenet, regardless of what the holy texts or respected leaders dictate. However, each of the operating principles allow for personal choice and autonomy by allowing the option to choose to not participate. Therefore, no one is bound to participate due to religion. The concern here is that there would be a strong personal and spiritual reason to reject participating in the organ and tissue donation system. However, the above shows that this concern, from the basis of religious text, culture, and belief, is miniscule. Thus, there are no religious obstacles to the ethical integration of any model of ODT, so long as it allows an individual choice mechanism.
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Ethics of the presumed consent operating principle

For a presumed consent operating principle to be ethical informed consent must be clear. Individuals must be aware of presumed consent and must immediately receive simple but precise instructions for opting out. Without these two conditions, individuals cannot make a real choice, and through misinformation or a lack of information, may make a decision contrary to their ethical beliefs or preferences: a basic violation of human and religious rights. This would be a violation of the Canadian Charter of Rights and Freedoms: section 2a (“freedom of conscience and religion”), section 2b (“freedom of thought, belief, opinion and expression”), and section 7 (“the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice”). However, by simplifying the process and clearly laying out the opt-out procedure, individuals gain freedom of choice, while also theoretically increasing donor supply.

There are a number of other presumed consents operating in Canadian provinces. Consider autopsy: in the case of a suspicious death, the body will be examined by a coroner to determine cause of death automatically. This is the same sort of “violation” of a dead body as the procurement of organs. Moreover, autopsies are the exclusive purview of the coroner, meaning there is no opt-out option. In every Canadian province, if the coroner declares a death suspicious and orders an autopsy, neither the family’s wishes nor the pre-mortem wishes of the deceased can overrule the decision. Given that autopsy is an accepted practice despite the lack of ability to refuse, the presumed consent operating
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principle must be considered as equally acceptable, if not more so, given the provisions for individual choice.

In the rare event that presumption of consent violates religious belief, policy generally prioritizes treatment. Consistently, nearly every Canadian province has chosen to override a patient’s desires in favour of medical treatment, particularly when children are involved. For example, many cases have occurred where a Jehovah’s Witness forcibly received a blood transfusion despite the direct refusal of the patient or legal guardians (Doyle 2002; Guichon and Mitchell 2006). Consider the Saskatchewan case of Tyrell Dueck, a young boy legally ordered to undergo chemotherapy even though he refused it on religious grounds (Kondro, 2006). This is not a perfect comparison, as the law was quicker to intervene because it was a case of child welfare and it was deemed a child cannot properly evaluate the decision to refuse treatment (Gesundheit et al. 2007). What this case does show, however, is that the state is perfectly willing to override the will of the family even on religious grounds and that the state is most often favour of living at almost all costs. This shows a clear precedence for making the assumption that residents would prefer to improve quality of life while minimizing harm. The next logical step is to assume that residents are unable to experience harm after death and that they want to improve the quality of life of those around them, which is the foundation of the presumed consent operating principle. It is readily apparent, given the above, that the presumed consent operating principle is ethically compatible with the values held by a majority of Canadians. The presumed consent operating principle is comparable
to all of the currently listed accepted practices listed prior and includes provisions allowing refusal, giving it even greater ethical standing.

*The ethics of the reciprocal altruism operating principle*

Reciprocal altruism is a concept from evolutionary biology where an animal will temporarily reduce its fitness and act in a way that benefits another, believing that someone else will reduce their fitness for its benefit at some unspecified point in the future (Trivers, 1971). For example, vampire bats will starve to death if they do not feed on two consecutive nights. As such, individuals will often feed each other from their blood stores if one has gone two nights without feeding. As a matter of enforcement, the group ostracizes a bat that refuses to feed another (DeNault and McFarlane, 1995).

In theory, everyone chooses to donate out of fear of not being able to participate in the system. If everyone is donating, then everyone is on the priority list and there is no unequal access as they all share the same status. Society benefits as a result: increased (hypothetically full) participation in the organ donation system, maximum efficiency in terms of receiving new organs, and minimizing long-term treatment costs. For those reasons Arthur Caplan (2009), director of the Center for Bioethics at University of Pennsylvania, has argued that reciprocal altruism is ethical for any health procedure.

Reciprocal altruism does not address the ethical concern regarding the system’s penalty for those who chose not to participate in the organ donation system. The operating principle does not account for personal belief and focuses
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solely on incentivizing its desired behaviour. When making the recommendations upon which the law was ultimately based, Israel’s National Transplant Centre defended against the coercion argument with two suppositions (Lavee et al. 2010). First, the probability of requiring an organ transplant is so low that the expected benefit that comes from signing a donor card approaches zero. While this may not make the decision entirely altruistic, the National Transplant Centre define it as “predominantly altruistic.” Second, if the policy works, they are contributing to the fundamental goal of medicine: improved health outcomes. According to Lavee et al. (2010) “Mutually exclusive ethical imperatives compete, leading to ethical tension; we believe utility tips the balance in favour of the new policy.” However, the first argument neglects that even though the expected utility from signing a donor card approaches zero, human beings have a poor capacity for rational risk perception, which means risk adverse citizens will pay a high cost in terms of stress if they opt out of the system. This not only refutes the “predominant altruism” argument, but also induces additional harm not addressed by their utility theory.

Another ethical challenge to the reciprocal altruism operating principle is that it rewards patients who have first-degree relatives who are organ donors while defaulting to next of kin (first-degree relatives) to provide consent. This creates a principal-agent problem—when one individual (the principal) hires or otherwise engages another (the agent) to represent his or her interests. A principle-agent problem is when the interests and incentives of the agent do not align with those of the principle. For example, consider a busy professor who
hires a teaching assistant for a class full of the teaching assistant’s friends. The professor’s interests are having the students’ work assessed for quality, while the teaching assistant’s incentives include giving his friends easy marks for social reasons. Although the teaching assistant does have some incentive to impress the professor and perform to a certain standard, if the incentive to simply hand out marks out of friendship is strong enough it creates a conflict.

In the case of the reciprocal altruism operating principle, an individual relies on his or her next of kin to represent their desire to participate or to not participate in the organ and tissue donation system. However, this introduces a moral hazard. The incentive for the next of kin is to consent to donation, regardless of the individual’s wishes, as they will receive priority within the queue, should they ever require a transplant. This is not to suggest that the incentive is so powerful that no one could possibly have the moral fortitude to respect their loved ones’ wishes, but the system creates the issue, which is not addressed by any mechanism or safeguard. This is a clear ethical failing on the part of this operating principle; the state should not put individuals in the position to be forced to choose between their own best interests and the wishes of their loved ones.

There is no credible argument for limiting a person’s ability to assert their rights regarding the handling of their body after death. This is the foundation for this thesis’ rejection of the mandatory consent operating principle. Another concern is that most public services and organizations do not embrace an
equivalent retaliation strategy. For example, it is not ethical to refuse police services to criminals. Thus there is no ethical case for the reciprocal altruism operating principle in Canada.

*The ethics of the legitimate market-based operating principle*

Some bioethicists feel that the very concept of trade for organs is unethical, not the least of which is the World Health Organization (Caplan et al. 2009), which draws parallels to prostitution and slavery and views selling organs as the commoditization of human beings. When describing ethical ODT systems, bioethicists often cite altruism as a requirement for donors, believing that providing benefit to another person, not financial compensation should be the incentive for donation. The legitimate market-based operating principle introduces a much deeper set of ethical issues.

A principal concern with the legitimate market-based operating principle is distribution according to income or wealth. It is unethical to deny a potential recipient a transplant solely due to a lack of economic resources (Flaman 1994). It is also important to be cognizant of which groups tend to be donors and which tend to be recipients, as it would be unethical to establish a system that engenders privileged groups to take advantage of marginalized groups (Schepers-Hughes 2003a). Furthermore, individual autonomy can only be respected if the individual faces no systemic pressures regarding choice. Poverty can influence individuals to make desperate choices. Therefore, a donation is involuntary and thus unethical in circumstances of extreme wealth disparity (Schepers-Hughes
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2003b). It is also crucial to consider donor health so they do not experience unreasonable risk (Truog 2005).

However, the Iranian system does contain numerous ethical considerations. First, it does not rely on a state agency or a private broker service (Ghods and Mahdavi 2007). Instead, once a patient has been identified as being unable to find a match with a willing relative or a cadaver donation, they apply to the non-profit, volunteer-run Dialysis and Transplant Patient Association (DATPA) who matches them to a potential registered donor (Tabarrok 2010).

Next, the state funds all related hospital expenses (Matas 2004). This means no one benefits financially from the transaction except for the donor. This relieves some concern for a principal-agent problem and concerns of individual coercion, forcing people into donation. The paid donation system also avoids allegations of “organ farming” by being the last resort donation pool, as the DATPA will only consider an application after exhausting all conventional donation methods.

A reasonable concern of this kind of program is that it is essentially a transfer from the young and poor to the old and rich: well-educated, well-to-do recipients can take advantage of poor, uneducated donors. Table 3.3 summarizes the demographic results of Ghods and Savaj’s (2006) study of 500 donors and their matched recipients:
### Table 3.3: Iranian Kidney Donor and Recipient Demographics

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Donors</th>
<th>Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illiterate</td>
<td>6.0 %</td>
<td>18.0 %</td>
</tr>
<tr>
<td>Elementary School</td>
<td>24.4 %</td>
<td>20.0 %</td>
</tr>
<tr>
<td>High School</td>
<td>63.3%</td>
<td>50.8%</td>
</tr>
<tr>
<td>University</td>
<td>6.3%</td>
<td>11.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Socioeconomic Class</th>
<th>Donors</th>
<th>Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>84 %</td>
<td>50.4 %</td>
</tr>
<tr>
<td>Middle Class</td>
<td>16 %</td>
<td>36.2 %</td>
</tr>
<tr>
<td>Rich</td>
<td>0 %</td>
<td>13.4 %</td>
</tr>
</tbody>
</table>

Source: Ghods and Savaj (2006)
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The key finding here is that recipients have more evenly distributed levels of education, with donors more often being at the high school level of education. The socioeconomic class of donors is overwhelmingly poor; however, it is important to note that greater than 50 percent of all transplants are performed on poor recipients. Although obvious class disparities between the donors and recipients exist, they need not be as skewed as the Iranian case.

Quotas may help alleviate this inequity. The acceptable transfer between the classes, sexes and/or ethnic groups would have to be addressed before such a system could be adopted in Canada. Currently, there are not many Canadian examples of such systems, particularly in healthcare, as the system tends to operate blind to the patient’s characteristics save for medical necessity. A revised legitimate market-based operating system could operate similarly to designated positions of employment for marginalized groups; however, this still rests on determining the acceptable level of transfer between groups. Such a determination requires further research beyond the scope of this thesis.

Ghods and Savaj (2006) also showed that the paid live system did not limit cadaver donation, as between 2000 and 2005, the proportion of donations from cadaver kidneys steadily increased. They also suggest that the paid living non-relative donation system not only reduced coerced relative donations, but also severely crippled the black market organ donation and related criminal enterprises.
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However, there are two further concerns about this market-based approach. First, there is a non-trivial, long-term donor dissatisfaction rate, where donors later feel the compensation is insufficient (Scheper-Hughes 2003a). The second concern is the one most commonly cited by opponents of market-based legal trade model: most poor donors remain poor after compensation (Matas 2004). In fact, lack of long-term compensation is one of the main reasons for donor dis-satisfaction (Jha and Chugh 2006). Financial incentives also create a systemic pressure to withhold vital health information (such as medical history of diabetes or dialysis, or risky sexual behavior), which can lead to increased medical complications for both the recipient and the donor (Danovitch and Lietchman 2006). As a result, there are many complaints of consistent deterioration of health among the donors and “unacceptably high” levels of infection in recipients (Jha and Chugh 2006). In addition, worldwide, a market for organs tends to lead to exploitation of vulnerable people for the benefit of privileged groups:

The circulation of kidneys follows established routes of capital from South to North, from East to West, from poorer to more affluent bodies, from black and brown bodies to white ones, and from female to male or from poor, low status men to more affluent men. Women are rarely the recipients of purchased organs anywhere in the world. (Scheper-Hughes 2003b)

The Iranian system has made respectable progress in alleviating ethical concerns, particularly in contrast to the illegitimate market. For example, the
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design of the entire DATPA program, including their coordination with charities to cover compensation for poor recipients, ensures any individual equitable access, regardless of ability to pay. Ultimately, Iran’s lack of waitlist means that all citizens, regardless of income, have their health needs met. However, the ethical considerations are not sufficient to be considered as acceptable to a majority of Canadians. The net impact of the system shows inequitable transfer from poor to rich. Adopting such a model in Canada would require a large amount of public consultation in order to gauge the public’s tolerance for these types of transfers and the necessary barometer for ethical and equitable distribution. At the present time the legitimate market-based operating principle is not sufficiently ethical and there are no clear mechanisms or opportunities to improve it sufficiently.
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Are the systems viable in Canada?

The ability to be implemented into the current Canadian political sphere is the next criterion of analysis. Rose (2005) identifies three key requirements for the implementation of policy drawn from a foreign jurisdiction:

- **Space** – ensure that the new policy will not be crowded out by existing policy and/or commitments. As western nations typically already have institutions and programs functioning in all areas of policy, a new policy must mesh well with the existing policies, or be able to replace them with minimal resistance.

- **Resources** – consider not only fiscal and economic resources, but also the administration, legislation, and personnel required to put a policy into action.

- **Applicability** – differences between the home and foreign jurisdictions require consideration. If the home jurisdiction is sufficiently different in some characteristic relevant to the policy, implementation will not produce similar results.

For this reason, mandatory donation is not a possible operating principle. While it would certainly increase participation and transplantation rates, it lacks space within the current Canadian policy environment. It does not mesh well with the values held by a majority of Canadians with respect to individual rights and choice. The political will and ability required to implement such a policy does not exist, hence its lack of further consideration.
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Another vital factor to consider is legal viability. A policy with empirically proven optimal results, enormous economic advantages, and unanimous public and political support still requires legal authorization. This section will examine the space for a potential policy implementation with a particular focus on the legal viability of the operating principles. This will be done in terms of their conflict with existing statutes and legislation; the legal opinions surrounding the precedent and ability of a jurisdiction to authorize or regulate such models; and the rights of the people and the state as they relate to the models.

The result of the intervention is arguably the most important factor in selecting which new policies to adopt or which changes to make to existing ones. This thesis operates under the hypothesis that the underlying problem in the current system is a donor organ supply shortage. Metrics such as percentage of population participating in the organ procurement program or number of evaluations of potential donors performed are often considered as metrics of analysis. Although, like all of healthcare, organ and tissue donation and transplantation (ODT) is a complicated system that is not easily profiled by a single result considered in isolation, the goal of an ODT system is to provide transplants. Thus assessing the impact of a particular model of organ and tissue donation and transplantation, it is apparent that the metric of analysis would be simply the number of transplantations performed. As argued earlier in this thesis, transplants are the most effective current treatment to end-stage organ failure (both financially and in terms of health outcomes). Thus, the ultimate goal
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of any policy intervention in ODT is simply the number of transplants performed, under the constraints of ethics and viability.

*Viability of the presumed consent operating principle*

The presumed consent operating principle is not popular among Canadians, despite its popularity in the literature. There is only 57 percent support for such a system in Canada (CIHI 2001). There is sufficient space for the policy: as none of the agencies and institutions currently involved in ODT (OPOs, CBS, OTDT etc.) would require any structural changes. The onus of consent is simply reversed, it cleanly replaces existing legislation without interrupting or altering the mandate of any stakeholders.

Implementation would be virtually costless, with only the costs of passing the legislation and enacting the law being incurred directly. This policy would lead to increased health care costs through the increased use of the transplantation system if presumed consent is effective at increasing the donor rate. However because transplantation has previously been shown to be the most effective treatment option, these increases in cost will be offset by even greater reductions in healthcare costs for alternative treatment methods such as dialysis, as well as improved economic outcomes due to the increased productivity and less morbidity and deaths. In theory, a presumed consent organ and tissue donation operating principle would have almost immediate positive impacts for provinces in terms of health outcomes and labour productivity.
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To handle implementation properly, the government could adopt a widespread advertising and information campaign announcing the change. The policy is easily explained and readily understandable to the general public, so the focus could be more on the benefits of the policy: shortened waitlists, improved health outcomes, increased provincial income, improved labour productivity, and less money spent on expensive procedures such as dialysis. The government could also point out the increasing demand rate for organ transplantation and frame the narrative around the expected future costs and burden of treatment under the current system. In addition, with the rise of end stage renal failure across all provinces, there is a clear argument for sustainability because the system change provides a cost-effective solution that would sustain the system while limiting ballooning costs. Furthermore, the government must make information available on the ethics of the procedure, showing how most religions are not opposed to the idea and how the new system will continue to allow any individual to opt out.

The second recommended government action is a re-evaluation of the current opt-in procedures, which would now become the process to opt out. First, the government must streamline and simplify the process as much as possible to ensure the strongest ethical case for the system. Next, the government could consider online forms or a mail-out issued across the province to allow everyone the opportunity to opt out before the system is in place. However, this would not be sufficient because the current requested consent
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system is not very complicated; inertia more than complexity keeps enrolments down.

To satiate this, for a year after the announcement, the provincial health ministries could hire temporary employees whose entire job is to assist people through the opt-out system. They should be placed in every geographic region of the province. The government could also consider sending a mobile unit of trained personnel throughout the province, going between communities and setting up sessions to help walk people through the process. Doing so will ensure that everyone has full opportunity to make his or her choice and guarantee full ethical compliance. The cost would be non-continuous, relatively small, not a significant budget burden, and more be a net benefit after the first few years of improved donations.

The public perception of bureaucracy can be overwhelming and can cause concern for those who would like to opt out but may be too intimidated to seek out how. Hiring specific ministry personnel would not only keep the ethically transparent but would also disseminate knowledge and skills that will help inform the population of the opt-out policy for years after. Overall, the policy is easily integrated into the current policy environment, ethically sound and virtually costless to implement. The proposed program to send out a mobile unit would only be salaries of a handful of employees over 12 months. It provides immediate tangible benefits. Implemented as outlined above, this sort of
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operating principle is viable according to the space and resource criteria of Rose (2005).

The legal aspect of the space criteria is more complex. There is significant literature on the presumed consent operating principle. Many papers make a simple assumption about presumed consent: unless the potential donor has made any request to not participate, they are willing donors and belong in the ODT system. However, this is a flawed assumption because, traditionally, there is a lack of any mechanism to allow an individual to formally opt out. Thus, health practitioners often rely on the next of kin. Next of kin play an important role in the organ donation process as they often acting as surrogates for a potential donor.

Another assumption often made about presumed consent is that the systems are relatively homogeneous. However, legally speaking, they are disparate, particularly in how they address the role of the next of kin. Kennedy et al. (1998) identify the five subsystems of consent for organ donation. They identify each of the subsystems by when permission to procure organs is legally granted:

- Only with the consent of the person lawfully in possession of the body and subject to express objection of the deceased or objection of the relatives, if available (UK).
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- After the relatives have been informed of the intention to remove organs, but irrespective of their consent, with the exception for that of the nearest relative (Norway).

- Once it has been ascertained that the relatives do not object (Italy).

- Where the dead person had not expressed an objection, the relatives confirm this and consent is then presumed (Belgium).

- Irrespective of the relatives' views (Austria).

We can see that these laws somewhat blur the lines between presumed consent and requested consent systems. What makes the distinction even more convoluted is that according to Coppen et al. (2005):

“countries may differ in their laws concerning consent systems, but in practice differences turn out to be much smaller. In their analysis of the national transplantation laws, and interviews with several contacts in these countries, they have shown that relatives always seem to play a certain role in the opting-out systems and that in practice these systems do not always work strictly as such.”

This puts the state in the problematic legal position of potentially opposing relatives and next of kin over who maintains the legal authority to provide consent for a deceased’s organ to enter an ODT system.
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With numerous conflicting legal opinions and results in practice, ownership of biological material is often a volatile legal situation. In many ways, this is analogous to the controversial legal situations revolving around the “right to die” and who has legal authority over patients in vegetative states. Because of these pressures, even states with strict legislation around presumed consent will default to a position of deference towards family members and next of kin.

Gevers et al. (2004) reveal, “Even in Austria, where according to the law relatives have no role at all, apparently they are asked in most cases whether they can agree with organ removal” (183). The motivation for deference to next of kin, in spite of a lack of legal responsibility to do so, relates to custom and a fear of negative publicity, which could further decrease participation and support for ODT (Gevers et al. 2004). The result is the strongest legal barrier to presumed consent: the practical difference between requested consent and presumed consent systems is often negligible.

In order for Canada to adopt a presumed consent operating principle, there needs to be systemic changes to the practices and culture of health practitioners involved in ODT. This must include legal protection for organ procurement agencies based on unambiguous statutes that clearly dictate who maintains the legal authority to assess potential donor consent. Furthermore, if the mandate is going to be a presumption of consent unless there is a clear objection from the patient on record, then the onus is on the state to collect these objections formally, as discussed in the ethics section, and to establish the laws and make citizens aware of the new policy. Without clear rules and regulations around the
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collection and determination of consent, current legal barriers make it difficult to
distinguish what the practical differences would be upon implementing presumed
consent. Without those distinctions, it is difficult to make a case recommending
the adoption of a presumed consent operating principle as it would operate
identically to a requested consent operating principle in practice.

The next step is to assess the applicability of the presumed consent
operating principle and estimate its impact on Canadian transplantation rates.
Using a data set of 22 countries over a 10-year span, Abadie and Gay (2006) show
positive effects, including “sizeable and positive effect on donation rates.” In
addition, Gimbel et al. (2003) credit an “opt-out default position” with a 56.5
percent increase in the donation rate per million in European countries. Johnson
and Goldstein (2003) replicated the same findings, with a smaller, but still
statistically significant, increase with a broader data set. Furthermore, Roels and
De Meester (1996), in their analysis of heart and lung transplantation and
donation, found “rates of heart and lung donation were at least twice as high in
the two countries with presumed-consent legislation as in the two countries that
rely on a policy of explicit consent from the donor’s next of kin” (176). More
support for presumed consent comes from Kennedy et al. (1998), who believe
that presumed consent “would achieve the same effect [as public and professional
education and measures to simplify the process of donation and retrieval of
organs] with greater certainty, as has been shown in countries that have changed
to this option” (1651). Likewise, Kittur et al. (1991) state that presumed consent
leads to more favourable organ donation rates on the whole, specifically citing
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Belgium which had “[i]n the three years since implementation of [presumed consent] law, [had] organ donation in Belgium...increase by 119%” (1442).

Finally, Bird and Harris (2010) go so far as to state “only a policy of presumed consent will substantially increase the number of organs available for transplantation”. They cite a report done in the UK by an Organ Donor Taskforce that analyzed published documents, such as longitudinal studies capturing pre- and post-presumed consent legislation donation rates and international comparisons. Bird and Harris state the report had positive results:

“the five before and after ‘presumed consent’ comparisons in three countries all documented substantial increases of at least five deceased organ donors per million population. The four out of the eight international comparisons that the report’s authors judged to be of good quality (for example, because of adjustment for cofactors) found that increases of around 25%, or three to six deceased donors per million population, were associated with presumed consent.”

Their own analyses also show favourable results, in the UK at least, where “[c]hanging the presumption... has the potential to deliver 68% (2880/4230) of the extra solid organ donors that mandatory donation would give”.

To account for potential cross-national differences, it is important to consider what factors drive increased participation in the ODT system. Gimbel et al. (2003) built a least-squares regression to determine the influential factors and how they contribute to organ donation rates. They chose four independent
variables and found them all to be significant. In order of significance, they were: “(1) having a presumed consent (opting-out) policy in practice, (2) number of transplant centers per million population, (3) percentage of the population enrolled in third-tier education, and (4) percentage of population that is Roman Catholic” (17).

Overall, the literature contains substantial evidence supporting the position that presumed consent achieves a larger organ and tissue supply. The next two figures best exemplify these results. Figure 4.1 shows the effective consent rates (the proportion of the population that has “opted-in” to the organ donor supply pool or failed to “opt out”, depending on the model in use in the particular jurisdiction). Figure 4.2 summarizes the cadaveric donation of organs per million (the number of organs post-mortem that are procured per million population).
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Figure 4.1: Effective Consent Rates by Country

Source: Ariely (2008)
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Figure 4.2: Cadaveric organ donations per million population - 2008

Source: Donate Life (2011)
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Figure 4.1 reveals a stark dichotomy. The nations with gold bars, on the left, have a requested consent system, whereas the blue bars, on the right, represent nations with a presumed consent system. This seems to demonstrate the effectiveness of a presumed consent system in improving participation rates in organ donation pools. Even countries with the similar languages, cultures, and histories have very different outcomes due to their contrasting policy choices. For example, Germany has an organ donation rate of 12 percent compared to Austria with a rate of almost 100%. Similarly, Denmark and Sweden contrast at 4.25 percent and 85.9 percent respectively. These pairs are regularly demonstrated to be very apt for comparison, as they exist within the same “clusters” based on a wide range of metrics. This is best identified by the meta-analysis of Ronen and Oded (1985) who describe Austria and Germany as part of a “Germanic” cluster and Denmark and Sweden as part of a “Nordic” cluster. Their similarities allow for a greater confidence in causal relationships between outcomes (in this case, the participation rate in the organ donor programs) and key differences (in this case, the philosophy of consent to organ donation).

Figure 4.1 demonstrates the extent to which the application of the presumed consent principle is capable of expanding the number of potential donors. However, as discussed above, potential donors do not necessarily equate with actual donors. It is important to verify if the increase in organ donor participation leads to the increase of actual donations as theorized. Figure 4.2 examines the evidence that a presumed consent system allows the donor supply of organs to catch up to the recipient demand.
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In Figure 4.2 orange figures represent presumed consent systems and blue figures represent requested consent systems. This graph appears to be a visual map of presumed consent and requested consent trends. The dichotomy is not nearly as strict as the participation rates, particularly the outliers of an exceptionally high United States and an exceptionally low Poland. However, other trends also become apparent, they are broken down again by the clusters described in Ronen and Oded (1985). Their “Latin European” cluster is made up of France, Belgium, Italy, Spain, and Portugal: five of the top six listed countries, with only the United States (a potential outlier) interrupting the sequence. Consider also that the “Anglo” cluster, which contains the United States, Canada, New Zealand, Australia, the United Kingdom, Ireland, and South Africa, has similar crowding. This raises the question of whether the seemingly clear division between presumed consent and requested consent can actually be attributed to the variation between the models. In fact, what is attributed to the operating principles may actually have more to do with another factor common among the clustered countries, such as a cultural preponderance or resistance to organ donation. It is clear that the relationship must be further evaluated before we accept better outcome claims.

Coppen et al. (2005) examines a closer causal relationship by considering the death rate of a particular jurisdiction, which provides a more accurate picture of potential donors. In their study of 10 European countries, they found that the predominant willing donor cause of death (that led to the procurement and transplantation process) was consistent regardless of the jurisdiction: “According
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to the annual reports of each national transplant center, approximately 80% of the deceased who become organ donors died of a cerebral vascular accident (CVA) or (traffic) accident” (1277).

This led them to run a regression analysis of the average number of organ donations per million per year against the average number of mortalities by CVA (which is more commonly referred to as a stroke) and automobile accident per million per year. The average was chosen to smooth out any potential outliers or skewness that may be caused by taking single point estimates. The averages came from the three most recent available years (2000-2002 for organ donation rates, 1999-2001 for mortality rates), with the exception of Belgium’s mortality rates, which, due to data limitations, were taken from an average of 1995-1997 data. This analysis showed a strong association between the number of transplantations performed per year and the selected mortality rates: “[t]here is a strong correlation between the donation rates and the mortality rates which are relevant for organ donation [Spearman’s ρ 0.81 (P-value < 0.01)]”. Countries with low donation rates usually have low mortality rates relevant for organ donation, while countries with high donation rates have high relevant mortality rates” (1277). By expanding this analysis, we can easily include Canada, this thesis’s jurisdiction of interest.

** Spearman’s rank correlation coefficient, rho (ρ), is a measure of how well the relationship between two variables can be described by a monotonic function. I.e. if one variable will cause a strict increase or decrease in the other, without a fixed magnitude of the impact.
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Coppen et al. (2005) used the World Health Organization “Health for All” database. As that database contains only European data, potential metrics were assessed to determine where to obtain equivalent information. The database uses The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, more commonly known as ICD-10. The two parameters most likely used in the study were 1730 SDR, motor vehicle traffic accidents, 0-64 per 100000 and 1340 SDR cerebrovascular diseases, 0-64 per 100000, both of which can be found under the 02 Mortality-Based Indicators tab. Theses correspond to ICD-10 codes of Traffic Accidents [V99] and Cerebrovascular Diseases [I60-I69].

Although the study itself reports the data as covering the 0-65 age bracket, given the data were divided into the 0-64 category or the all ages category, it is assumed the 65 is erroneous or an interpretation that 0-64 is actually 0-64.999.... which can readily be thought of as 0-65. Statistics Canada CANSIM table 1020551 contained the Canadian data for mortality rates per million for a number of age categories for both the previously mentioned ICD-10 codes. The results for all age categories from less than 1 year to 60-64 were aggregated to achieve the same measurements. The three-year average for combined mortality rates was taken from 2000-2002 for data availability purposes. The average deceased

†† Note that stroke, or Cerebrovascular Accident as the study refers to it, is typically defined as only the ailments under ICD-10 codes I61-I64: Intercerebral haemorrhage, other non-traumatic intracranial haemorrhage, cerebral infarction and stroke - not specified as hemorrhage or infarction. Given that the “Health for All Database” does not allow for a more specific breakdown than Cerebrovascular Diseases [I60-I69], this will be the definition used for this section of the analysis and for determining the Canadian relevant mortality rates
organ donor per million was calculated from data provided by CIHI’s Canadian Organ Replacement Register (CORR) divided by the population of Canada (in millions) available from Statistics Canada CANSIM table 510001. Although the number of deceased organ donors in 2000 was relatively high to the 10-year average, described by a parliamentary report as a “small spikes of 471,” this outlier does not significantly affect the three-year average due to the preference of position over magnitude in the Spearman process. Therefore, the same date range of 2000-2002 was used. The inclusion of Canada into the data analysis provides a similar association (Spearman’s $\rho$ equal to 0.77 with p-value $< 0.01$), which supports the claims made by Coppen et al. Figure 4.3 shows the relationship.
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Figure 4.3: Relationship between relevant mortality rates and organ donors

Source: Coppen et al. (2005), CORR (2012), CANSIM tables 1020551/510001
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While Figure 4.3 shows a cluster of nations under the requested consent model\(^{11}\) lower than the typical organ donation rate per million under the presumed consent operating principle, the model also shows that nations with requested consent all tended to have very low mortality. Yet, Coppen et al. (2005) note disparities among nations under presumed consent: “countries with an opting-in system vary in their donor efficiency rate. This variability is also found in the countries with an opting-out system, which indicates that there is no correlation between consent systems and organ donation rates” (1277). Moreover, they find no statistically significant evidence to differentiate between presumed consent and requested consent jurisdictions: “when donation rates are controlled for differences in relevant mortality there is no significant influence of the systems on these rates” (1278). Though this does not prove a direct causal link between organ donor rates and death due to stroke or motor vehicle accidents, it is evidence that the correlation exists and that the driving factor may in fact be mortality rates rather than jurisdictional operating principles.

The presumed consent operating principle certainly passes the first two of Rose’s (2005) criteria. There are no resource constraints and there is sufficient space for the policy, given the adaptations suggested for legal considerations to distinguish it from working like a requested consent operating principle in practice. This means the presumed consent operating principle is certainly a viable policy option. However, the evidence around effectiveness is somewhat

\(^{11}\) In the original analysis, Coppen et al. listed the United Kingdom as presumed consent operating principle, which is erroneous, it has been corrected here
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mixed. Although the correlation points to mortality rates playing a bigger role than operating principles, there are few systems that truly presume consent and do not default to consultation with next of kin. The theory behind the presumed consent operating principle is still valid, if the provinces were to take a strong stance about presuming consent and taking only the individual’s opposition into effect, it may still create gains in Canada’s transplantation rate.

Viability of the reciprocal altruism operating principle

Similar to presumed consent, a thorough campaign explaining the reciprocal altruism operating policy would be necessary. Unlike presumed consent, this model is complicated and easily misrepresented. When Israel implemented the policy, they launched a “massive, multilingual, multimedia campaign” (Lavee et al. 2010). The goal was to provide sufficient education to the entire citizenry and build a cornerstone of informed consent. They did so because, in this system, the nuances of waiting lists can be obtuse and cumbersome, regardless of education level and background. To allow potential donors to make the appropriate decision about participation, it is incumbent upon any state that decides to implement this type of regime to build a knowledge base that is accessible at all levels.

Regardless, the potential divisiveness of this issue warrants particular consideration. From a Canadian context, it is especially important because a two-tiered system of prioritizing organ recipients may be a violation of the Canada Health Act (CHA). Section 10 of the CHA requires that all health services must
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be universal, specifying they must be provided on “uniform terms and conditions”. Similarly, section 12 a. says that everyone must have access to health services "on uniform terms and conditions, unprecluded, unimpeded, either directly or indirectly, by charges (user charges or extra-billing) or other means (age, health status or financial circumstances)". Canadians have a very high regard for the Canada Health Act. As such, they may see impeding access to organs or non-uniformly providing services as clear disregard for the central tenets of modern Canadian healthcare.

Although the ethical problems are potentially manageable, they remain divisive. Even more challenging than the ethical conundrum is the potential challenge of the CHA. Creating religious animosity and attempt to introduce a definitive two-tiered element into the system is risky regardless of financial implications. This is particularly ill advised for systems with little more than a simple opt-out program. Therefore, the best strategy for any Canadian jurisdiction interested in this approach would be to gather data from Israel over the next few years and re-evaluate when there are clear results.

Reciprocal altruism presents greater legal complexities than other operating principles. Although once again it avoids any issues around ownership of the organs, while conforming to existing standards of consent as a matter of personal and/or next of kin preference, it is based upon a prioritization of patients according to non-medical criteria. As mentioned earlier, the biggest legal barrier is the Canada Health Act and its guarantees about equal treatment.
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As such, adopting the reciprocal altruism operating principle would require an assessment of the potential challenges to the system under the CHA. In addition, it would involve detailed assessments of who could potentially make such challenges and which sections they might cite.

However, reciprocal altruism can present its ranking as medical necessity, given that those who have donated organs previously are much more vulnerable to end-stage organ failure, particularly those with kidney or liver sections. By prioritizing those related to organ donors, this model could easily comply with the CHA and avoid equality-based criticisms. Ultimately, reciprocal altruism is feasible given the ethical issues surrounding relative-based decision-making and incenting under Israel's implementation.

As only the Israeli system uses reciprocal altruism, and it is still in its infancy, there is limited peer-reviewed data or analysis to support or discredit its efficacy. Media reporting shows improved results in 2011, with a 64 percent increase over 2010 live kidney donation rates (Even 2012). Although, the reimbursement program started in the summer of 2010 may be related. Israel was also known to lag well behind most Western nations (Lavee et al. 2010), so small nominal gains can translate into large percentage gains. At this point, it would not be prudent to make any judgments about the effectiveness of reciprocal altruism. Yet, it will be fertile research ground and hopefully over the coming years, there will be an influx of reporting on how reciprocal altruism influences donation and transplantation rates. It will also be fascinating to see if
other countries adopt this system and how they fare relative to Israel.
Unfortunately, this sort of speculation cannot provide any insight or evidence for recommendations in the present and requires further research before drawing conclusions.

Even if evidence around improvements to outcomes were available, the reciprocal altruism operating principle does not appear very viable in Canada. Although there is space for the policy in that it does not disrupt the existing institutions and parallel policies, the legal barriers to implementation are too difficult to overcome. Combined with the ethical issues, the reciprocal altruism operating principle is not well suited to the current policy environment in Canada.

**Viability of the legitimate market-based operating principle**

Initially, the legitimate market-based operating principle may seem antithetical to the publicly provided system. However, there is a strong precedent for this type of policy in Canada. In 2011, Saskatchewan entered into a partnership with the Kidney Foundation to provide up to $5,500 per kidney to defray travel costs, lost wages due to surgery, or any other donor expenses (Carlson 2011). This is only a small conceptual leap from paying for the organ. The economics also provide a very strong case for a market-based system.

In particular, economics supports a market-based system for live kidney organ transplantation. Dialysis is an expensive process, costing up to $70,000 per year per patient (Major 2008). With end-stage renal disease occurring at
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younger and younger median ages, and the rising rates of Diabetes mellitus, Canada faces an impending financial crisis based on nephrology alone. Economic studies place figures as low as $15,500 per kidney being enough to relieve the shortage and as high as $90,000 per kidney still being a cost-effective alternative (Whiting et al. 2000 and Becker and Elías 2007). The figures were done for the American market, but it is assumed Canada’s figures would be comparable. With that in mind, live donation is typically the only type of donation that would benefit from this model. Nonetheless, to improve the participation rates for cadaver donation, Canada would have to study the payment levels to determine the most cost effective option.

A predominant issue is maintaining equity through system management. Clearly, it would be financially beneficial to reduce the expensive burden of dialysis and death with productive organ replacement. While many suggest it is a logical progression from current policy, it crosses established taboos. For example, paying for organs may conflict with the morality of many citizens and may cause divisive debates and/or political upheaval. Therefore, if the policy were to be considered for adoption, it would be prudent to have town hall meetings and opportunities for the populace to ask questions or raise their concerns. At this point, it is not clear whether support could be found for such a policy.

Legitimate market-based operating principles have a relatively simple legal relationship: simply the repeal of previous legislation that forbids body part
transactions. If the legitimate market-based operating principle were implemented similar to the Iranian method, the state’s role consist of the operation of a third-party agency that helps match potential donors to transplantees and the facilitation of charity funds or other benefits to enable the transaction. As the state would neither be a direct payer nor be the authority in the transaction, this model would sidestep a number of the issues that could arise from the direct purchase of organs.

In this model, the state would not own organs, nor would it have influence on who decides to participate as either a buyer or a seller. They would simply be a facilitator, ensuring fair transactions by certifying the proper accreditation and regulation of all professional services involved. This is much like the government’s role in the housing market. It ensures a regulatory standard for realtors and provides financial facilitation through the Canadian Housing and Mortgage Corporation, but never actually takes possession of the homes nor exerts influence on buyers or sellers. Ultimately, this minimizes potentially divisive legal opinions required on potential state-ownership or on distribution of organs and makes the legal case around legitimate market-based operating principles relatively straightforward.

The legitimate market-based operating principle, like reciprocal altruism, only has data from one nation. As such, this limited body of research lacks any suitable comparative studies regarding the effectiveness of the model. However, the Iranian system has impressive results for organ donation and
transplantation. Since 1999, its legitimate market-based operating principle has the unique distinction of being the sole jurisdiction without a wait list for renal transplants (Ghods 2002). Nonetheless, the legitimate market-based operating principle focuses almost exclusively on live donation, as opposed to the focus on cadaveric donation of the other two. Moreover, given its short existence, Iran has also made substantial improvements in their cadaveric organ donation system (Larijani, Zahedi and Taheri 2006; Ghods and Madhavi 2007), but this is independent of their unique legitimate market-based operating principle as they only allow live donation purchases.

There is little scholarly work about the replication of results outside of Iran. Nevertheless, there is no theoretical basis discrediting the use of the profit incentive elsewhere. The fact that these sorts of practices occur illegally in every continent suggests that the same incentives prevail universally even if there would likely be a disparity between the price point of a kidney in Iran as compared to the price point for one in Canada. To provide context, payments for kidneys and livers in the United States have been estimated at between $7,600-$27,700 USD and $18,700-$69,300 USD, respectively (Becker and Elías 2007). Although these figures reflect shortages found in the United States, we can estimate that the Canadian figures would be similar, given the fiscal efficiencies that exist in renal transplants versus on-going dialysis. Of note, if Canada were to adopt a legal market-based trade as a model, thorough analysis using Canadian data is necessary in order to maximize economic gain—not only for reducing
CHAPTER FOUR: POLICY IMPLICATIONS

alternative treatment costs, but in improving health outcomes and productivity gains of patients suffering from end-stage organ failure.

The outcomes of the legitimate market-based operating principle are impressive, but the other criteria for viability are certainly not met. Although there would not likely be any resource constraints, due to the cost-effectiveness of organ transplants, it is not clear there is space for the policy. The legal barriers around property rights of biological material and the ability to sell tissues and organs and the difficulty OPOs may have in adopting a DAPTA-like role, or having to co-operate with another, external body operating in that function provide obstacles to integration. Most importantly, there are severe ethical issues for which no apparent solutions exist. The legitimate market-based operating principle is not a viable policy option for Canada, given the current political environment.
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Why single out Saskatchewan for study?

The international focus of this thesis has not borne optimistic results. Canada cannot simply adopt policies seen elsewhere and anticipate similar successes. There are many ethical, political, and practical barriers for immediate change of this kind. As such, the first step to improving organ donation and transplantation (ODT) is benchmarking and adopting the most effective provincial policies and spreading them to all provinces. In Canada, Saskatchewan is a unique case; as the poorest performer, it is easiest to identify the types of barriers and poor policies which are negatively impacting the donation rate. Saskatchewan is also a readily accessible case study because of its proximity and the availability of interview data from officials who operate within the healthcare system. The policy implications of this specific type of case study demonstrate that there is space for interprovincial cooperation and knowledge transfer, which allows for better results across the country as provinces benchmark best practices. Provincial policy sharing meets the guidelines laid out in Rose (2005) as all provinces operate under similar healthcare systems guided by the federal government, there is sufficient space for them to institute the successful policies from the highest-performing jurisdictions. Moreover, resources should not be an issue, as improvements to the system have resulted in net savings through the cost-effectiveness of an increased transplantation rate. In addition, given that they are all provinces of the same country, there should be minimal interjurisdictional differences to hamper replication of success.
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

How does Saskatchewan perform?

As seen in Chapter One, Canada performs poorly in ODT and Saskatchewan performs poorly relative to the rest of Canada. Figure 5.1 shows the raw number of transplants performed by OPO for 2010.
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Figure 5.1: Transplants Performed (Nominal Numbers)

Source: CORR, 2011b
Clearly, with only two transplants performed in 2010, Saskatchewan sits at the bottom. For 2011, it is likely that Saskatchewan will report zero transplants. As shocking as this number is, it is a nominal number and therefore not a very useful comparison. Differences can easily be a result of differing provincial population sizes. Typically, per capita data use allows for standardization; however, this is not practical because organ procurement organizations (OPOs) operate across multiple jurisdictions, aggregate with territories, and cover for other provinces that do not provide certain services. For example, cardiac transplants do not take place in Manitoba. Thus all Manitoba residents who need heart transplants count in the jurisdiction where the transplant occurs. Consequently, simply using provincial population figures will not provide accurate context. Instead, standardization will take place as a ratio of completed transplants to remaining waitlist patients. This will function as a progress report, showing the jurisdictions that are best at responding to the needs of its awaiting recipients.
Figure 5.2: Transplants Performed (Ratio)

2010 Organ Transplantations
(Ratio: Transplants to Wait List)

Source: CORR, 2011b
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Figure 5.2 still shows that Saskatchewan lags significantly behind the rest of Canada. Saskatchewan’s poor performance is somewhat attributable to the fact that there was an unfilled transplant surgeon position due to illness. The position also went unfilled throughout 2011, which is a major contributor to the low expected numbers for this period. It bears further analysis of the time trends of transplantation in Saskatchewan. Figure 5.3 shows adult kidney transplantations (the only procedure performed in Saskatchewan) as a ratio of number performed to number on waitlist.
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Figure 5.3: Time Series of Adult Kidney Transplants by OPO (Ratio)

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Here we can see that although Saskatchewan’s especially poor 2010 performance was a bit of an outlier, the trend has been downward for years. A consistent laggard, even among the three poorest performing provinces, Saskatchewan sits at the absolute bottom for all periods except 2007. Note the waitlist for 2007 was only 100, well below its average of 150 for the following 3 years, which lead to its increased ratio. Yet it only barely surpasses Manitoba and Québec.

Although this thesis proves that Saskatchewan performs poorly in Canada, it has not confirmed the consequences of Saskatchewan’s poor outcomes. The previous Chapters emphasize the gains that come with transplants, but does not touch on the costs of neglecting them. Table 5.1 presents the age-standardized mortality rate for renal conditions (nephritis) in Canada.
Table 5.1: Age-Standardized Mortality Rate for Renal Failure per 100,000

<table>
<thead>
<tr>
<th>Cause of Death (ICD-10): Nephritis, nephrotic syndrome and nephrosis [N00-N07, N17-N19, N25-N27]</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>8.2</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>14.1</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>9.1</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>8.8</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>10.6</td>
</tr>
<tr>
<td>Quebec</td>
<td>8.4</td>
</tr>
<tr>
<td>Ontario</td>
<td>7.7</td>
</tr>
<tr>
<td>Manitoba</td>
<td>8.7</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>12.3</td>
</tr>
<tr>
<td>Alberta</td>
<td>7.7</td>
</tr>
<tr>
<td>British Columbia</td>
<td>7.2</td>
</tr>
</tbody>
</table>

Source: StatsCan Table 102-0552
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Table 5.1 clearly shows that Saskatchewan nearly leads the nation in deaths related to renal failure, falling only behind Newfoundland & Labrador. Trends over time are examined in Figure 5.4.
Figure 5.4: Time Series of Age-Standardized Renal Deaths

Source: StatsCan Table 102-0552
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Figure 5.4 shows that Newfoundland and Labrador tends to fluctuate, an artefact of a small population where small nominal changes lead to large standardized changes. Alternatively, Saskatchewan is increasing when the Canadian trend is slightly downwards. This implies that Saskatchewan’s poor policies not only lead to a higher death rate among patients with poor renal outcomes, but that they are worsening unlike the rest of the country.

What is the process like in Saskatchewan?

In Saskatchewan, the patient pathway to obtain an organ transplant is as follows\textsuperscript{55}: first, a general practitioner who refers you to a specialist sees you. Once the specialist confirms that you have end-stage organ failure with a prognosis of no recovery without a transplant, you enter the organ transplantation system. For all non-kidney organs, this means entering the queue in Alberta, Ontario, or, in special cases, Nova Scotia. You would then leave the Saskatchewan system and be handled by the OPO and healthcare system of the specific province with consultation, direction, and coordination with the Saskatchewan Transplant Program. Due to the severe nature of end-stage organ failure for these organs, this process is done at high-priority and transplants are required as soon as possible. Kidneys have a more manageable alternative—dialysis—so they are handled less urgently. The Saskatchewan Transplant Program handles end-stage renal failure entirely as kidney transplants can be done in Saskatoon at St. Paul’s Hospital.

\textsuperscript{55} From consultation with senior Regional Health Authority officials of Saskatchewan, under the condition of anonymity (August, 2011)
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

Once a nephrologist refers you to the Saskatchewan Transplant Program, you undergo a complete work-up to assess your serotype for matching to a potential donor and they identify potential surgical complications. For a parachute kidney, the term for a relatively young and healthy individual who only has end-stage renal disease with no further complications, the work-up will be completed in fewer than six months. If you have other co-morbidities or complications, such as advanced age, heart disease, diabetes mellitus, to name a few, your work-up will be prolonged as the Saskatchewan Transplant Program must coordinate with cardiology or other medical departments for other work and precautionary measures and tests. It is not unusual for these types of patients to have work-ups over 1 to 1 ½ years. Once the work-up is complete, you are put into the transplant queue. Transplants are queued in a first come, first served basis, where the first acceptable match to an available kidney is the longest-waiting match.

What is holding Saskatchewan back?

Saskatchewan has a very sophisticated procurement system, similar to that used by the Trillium Gift of Life Network, the OPO in Ontario. However, the Trillium Gift of Life Network sees much better outcomes. Saskatchewan is failing due to poor policy; Kleinman and Lowy (1989) released a paper on the state of organ donation in Canada, lauding Manitoba for incorporating a mandatory reporting law. According to the paper, in Manitoba and 40 of the U.S. states, attending physician had to report the death of any patient under their care to the jurisdiction’s organ procurement body for potential donor assessment. Kleinman
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

and Lowry write, “[mandatory reporting] represents a reasonable and more effective method of increasing the number of donor organs” (108). Both countries agreed. The United States established mandatory reporting as a federal law and every province except Saskatchewan currently uses it (Nakreiko 2009; Dodek 2003). Mandatory reporting is a low-cost solution to implement, requiring no additional infrastructure or capital and does not conflict with Saskatchewan’s current strategy. The current efforts to boost donation rates are an advertising campaign encouraging people to become donors and to talk to their families about their wishes around organ donation. In fact, the strategies would compliment each other, because although mandatory reporting would ensure the maximum number of screened candidates without the necessary permissions from next of kin an individual cannot be considered as an organ donor.

Most important, mandatory reporting fits well into Rose’s (2005) three key criteria. As it exists in all other jurisdictions across the country, there is certainly space for its implementation. The only cost is creating legislation, which can easily be taken from existing legislation elsewhere. Thus, the resource condition is satisfied. Given the limited number of interjurisdictional differences, the policy should potentially give Saskatchewan results similar to Ontario, which has both mandatory reporting and an OPO methodology that operates similar to Saskatchewan’s model.

Mandatory reporting policy is by no means a panacea. Although its low cost and universal use make it appealing, limitations exist. Dodek (2003) showed that despite using trained requesters in combination with mandatory reporting,
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

refusal rates remained constant and relatively high in Pennsylvania: 52 percent. While they managed to increase referrals and thus transplants, the policy alone does not address certain issues. Often, the language around mandatory reporting is ambiguous or sloppy. Consider British Columbia’s Human Tissue Gift Act of 1998. It required all hospitals to notify the Organ Procurement Organization, B.C. Transplant Agency, of deaths and undefined “impending” deaths (Dodek 2003). This created several issues: potential harm to patients by keeping them on elective ventilation and other measures until they could be assessed; ethical concerns around conflicts for attending medical personal as to when their responsibilities to patient to provide care end and where their legal obligation to the OPO begins; and causing undue stress to the patient and their next-of-kin prematurely or unnecessarily if they do not reach acceptable neurologically determined death criteria before cardiovascular determined death. Dodek (2003) points out the key to avoiding these kinds of issues is to use clearly defined language and to focus more on deceased patients rather than seeking out imminent deaths.

Given Saskatchewan’s strategy focuses around awareness and education, there are other lessons readily learned from other provinces. Transparency is an excellent resource to facilitate awareness and understanding of the ODT system. Compare the primary site for information in Saskatchewan to its equivalents in Manitoba, British Columbia or Ontario. In terms of organ donation and transplantation, Saskatchewan has two small pages on the labyrinthine Government of Saskatchewan website and a stand-alone social campaign website
CHAPTER FIVE: CASE STUDY - SASKATCHEWAN

with four notable figures providing quick synopses as to why they participate in the organ and tissue donation program. On the other hand, the other OPOs maintain stand-alone sites with details about the process of organ donation, frequently asked question pages, and a host of other resources. Trillium Gift of Life Network’s (TGLN) website is the gold standard in this regard. Whereas Saskatchewan’s campaign is based around a sticker that according to its own website “do[es] not guarantee a donation,” the TGLN website is filled with resources and information. They thoroughly describe the basics of organ donation, from what procedures are done to the difference between neurological and cardiac death, not to mention how it impacts donation. They include information on religious perspectives around donation, including pamphlets centred on the more common denominations, resources for students, teachers, healthcare professionals and donor families. Additionally, they have grief library materials, statistics and information about organ donation and transplantation within the province, and all of the manuals, videos, and training material health professionals need to stay up to speed with the program. Clearly, it is a model that Saskatchewan should adopt, an all-encompassing node for any information a member of the public would ever want. Another simple, immediate step that the province could take is to emulate TGLN’s available resources. A greater understanding of the process and the importance of ODT to the health outcomes of fellow residents allows individuals to be more informed when making their decision to participate.
CHAPTER SIX: CONCLUSION

Any change to the organ and tissue donation system in Canada must be ethical, politically viable, and produce better results than the current system. This thesis has shown that the Canadian system has lagged far behind the rest of the world when it comes to ODT. Although there have been improvements in the past few decades, they have not kept pace with the increasing rate of end-stage organ failure. In fact, without a major policy change the gap between demand and supply will continue to grow. This thesis examined three operating principles seen in other jurisdictions and assessed them according to the criteria of ethics, viability and outcomes.

A publicly-funded healthcare system operates on the assumption that it is in society's interest to improve health conditions. As such transplants show improved survival times, they qualify as a procedure which improves health outcomes and conditions. In addition, organ transplantation is cost-effective (Whiting et al. 2004, Machnicki, Seriai and Schnitzler 2006), which is not surprising considering that recipients of successful transplant can return to the labour force while avoiding costly medical interventions.

Presumed consent, popular in Western Europe, is an option with considerable support among professionals, citizens, and academics. Contrary to the requested consent operating principle, presumed consent simply reverses the onus of participation. Individual choice is still preserved as long as the mechanism of opting out is detailed clearly and promoted widely. However, for a true presumed consent operating principle, provincial governments would have to
CHAPTER SIX: CONCLUSION

take a strong stance by considering only the objections of the deceased, not those of the relatives or next of kin. They would have to implement a formal and regularly updated system of collecting such objections, and make this information readily available to health practitioners. Theoretically, doing so will lead to an increase in donated organs, but it may have insidious side effects. In fact, “some people may be so offended by the state’s presumption of their consent to organ procurement that, although they did not previously object to donation, they would now place an objection on record” (Vaetch 1991). Furthermore, such a loss of public support is problematic as a presuming consent operating principle “can only achieve its purpose (i.e. to yield more post mortem organs) if it is widely accepted by the health professions and by the public at large” (Gevers et al. 2004, 180).

A state with a presumed consent operating principle potentially carries no greater ethical burden than one with a requested consent operating principle. This requires a government to launch an advertising campaign to alert people of the policy change and make resources available to help guide individuals through the process so that they can still maintain their right of autonomous choice. Given these expenditures may not be much greater than the advertising and social media campaigns used under the current opt-in policy in Canada, and given the cost-savings generated by a higher rate of organ transplantation, there should be no fiscal implications for a government replacing a requested consent operating principle with a presumed consent operating principle.
CHAPTER SIX: CONCLUSION

Presumed consent is also a politically and legally viable policy. Using the criteria set out in Rose (2005), we see that there is space for the policy to exist in Canada, as it would simply be a reversal of burden in the existing policy, effectively replacing it with no change to existing institutions and with minimal new legislation. There are neither legal issues with its implementation nor any other policy conflicts to resolve.

Admittedly there is some ambiguity concerning the causal impact of differing consent practices. For example, mortality rates in a given region or country may affect outcomes. As discussed in Chapter Four, Spain is a world leader in rates of organ donation but this is strongly correlated with its extremely high rate of motor vehicle accident fatalities.

Reciprocal altruism involves many complications. However, a Canadian equivalent similar to the Israeli model discussed previously would create space for the policy—neatly replacing the existing operating principle with minimal fuss. However, there are legal concerns with using a reciprocal altruism operating principle in conjunction with the Canada Health Act. For that reason it may not be legally feasible to adopt this operating principle. This thesis also demonstrates that the reciprocal altruism operating principle would not be ethically acceptable in Canada. The principle imposes a sense of strict give-and-take justice and there are many issues with providing incentive for next of kin—often the principal sources of consent—to provide consent regardless the potential donor’s wishes. Ultimately, given the complete lack of any evidence one way or the other on
reciprocal altruism’s effectiveness, at best, this model requires further observation and a future reassessment.

The legitimate market-based operating principle delivers excellent results. These results are available at a minimal cost. Even if governments sponsored all donor payments, such payments would be less than the current cost of renal dialysis. While the operating principle, as implemented in Iran, is easily implementable, Canadians would likely be too uncomfortable with the idea of introducing direct patient-side financial compensation and incentives into the healthcare system. A legitimate market-based system carries negative connotations around wealthier patients buying better treatment; a contentious issue in the Canadian healthcare debate. Two-tiered healthcare, with wealthier patients purchasing jumps in queue, faster service, or otherwise unavailable treatment, is unacceptable to a majority of Canadians (Brooks 1993; Naylor 1999; DeCoster and Brownell 1997).

Furthermore, there is inherent inequity in the source of the organs, where donors are systemically disadvantaged and recipients tend to be privileged. Although Iran shows very good outcomes in live organ transplantation, it is difficult to ignore the fact that the source of the vast majority of organs are from the most vulnerable in society- the impoverished and the children of the impoverished who are not given a true choice. As such, it is difficult to make an ethical case for this operating principle, as the flow of organs invariably leads from the poor—the marginalized and the oppressed—to the wealthy. Moreover,
CHAPTER SIX: CONCLUSION

there is no clear way to build in the kind of ethical safeguards that would make this operating principle palatable the Canadian values that underpin universal healthcare. In addition, further donor examination would be required to ensure that the system would not induce a greater burden on the organ donation system or other healthcare sectors. If this model is to be Canada’s next step, the clear direction is to begin open discussions with Canadians to assess how receptive they would be to such a program and in order to determine the demographics of potential participants.

This thesis demonstrates that the Canadian provinces can benefit through increased cooperation with each other, extended knowledge sharing, and benchmarking best practices. In fact, Saskatchewan could easily improve outcomes by emulating provinces that are more successful. For example, the province could adopt a policy of mandatory reporting of all eligible deaths to the OPO. The next research step is to develop the logistics of these sorts of interprovincial collaborations. It is possible that an interprovincial agency, possibly based upon the Canadian Blood Services, which already facilitates interprovincial collaboration on a restricted number of tissue transplants, could be established for at least some abdominal and thoracic organ transplants.

Organ and tissue donation and transplantation is a tumultuous issue involving a number of crucial factors. Ultimately, Canadians themselves need to be involved in some capacity to provide guidance on any change involving values and ethics. This necessary conversation must occur throughout Canada and
CHAPTER SIX: CONCLUSION

needs to be underpinned by accurate information. Furthermore, Canadians need to fully comprehend the nature of death – particularly neurologically-determined death (NDD) and the beneficial impact of organ donation. This is currently a somewhat taboo discussion, and moreover, confusion surrounding NDD potentially confounds any discussion concerning all policy options. Without the underpinning of proper education all discussion around ODT becomes a polarized debate based on misinformation. The discussion must be carefully managed by provincial governments, either individually or in concert. Canada needs to step forward and encourage people to make this decision: inform themselves about the consequences and make their choice to participate well known to their relatives, to their health practitioners and most importantly, to the organ procurement organizations.

Much of the literature on organ donation is pessimistic. In fact, for Langone and Helderman (2003), “One of the ...most relevant [findings] to the practice of organ transplantation is the bleak forecast that even in a utopian situation in which consent was obtained for all potential donors so that all potential organ donations were retrieved, there would be an inadequate number to satisfy our country’s current and future needs” (706). There is not sufficient evidence that supports this cynical view. The system in Canada can, and must, be improved. Although the current situation is bleak, Canada’s poor performance cannot be left to reign unchecked.
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Of course, prevention is the ideal solution. The gold standard of any health improvement is the complete absence of illness. As such, the upstream prevention of end-stage organ failure is the most effective option. The determinants of health, reducing co-morbidities and other related conditions, and public health interventions, as in other health conditions, generally prevent end-stage organ failure. Consider end-stage respiratory failure, which requires a pulmonary transplant. The typical causes are chronic obstructive pulmonary disease (COPD), emphysema, idiopathic pulmonary fibrosis, and cystic fibrosis (Aetna intellihealth 2006). The upstream reduction strategies for end-stage respiratory failure are a repetition of the upstream reduction strategies for each of those conditions, such as air-quality interventions, anti-tobacco campaigns, genetic screening, and avoidance of pollutants (Lung Association 2010). These types of initiatives will lower the incidence of end-stage organ failure, which will lessen the demand for replacement organs and thus donors without any change to the operating principle downstream at the tertiary care level.

However, this thesis has shown that there are real policy changes that can be made. There are changes that are viable, ethical and provide positive outcomes. There is a wide array of options to choose from, particularly if a government is willing to put in the necessary work for consultation and education of the general public. There are many reasons to be optimistic about the state of ODT in Canada, although there is a long way to go from present standings.


BIBLIOGRAPHY


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# APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

<table>
<thead>
<tr>
<th>Religious Denomination</th>
<th>General Position</th>
<th>Additional References</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Methodist-Episcopal</td>
<td>Organ donation is encouraged as an act of love and charity.</td>
<td>N/A</td>
</tr>
<tr>
<td>(AME Zion)</td>
<td></td>
<td>“The Amish believe that since God created the human body, it is God who heals. However, nothing in the Amish understanding of the Bible forbids them from using modern medical services, including surgery, hospitalization, dental work, anesthesia, blood transfusions or immunization.” - John Hostetler, Amish Society</td>
</tr>
<tr>
<td>Amish-Mennonites</td>
<td>Organ donation is only permissible if it will result in improved well-being for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>the recipient.</td>
<td></td>
</tr>
</tbody>
</table>
| Anglican (Episcopalian)         | Organ donation is viewed as a spiritually acceptable practice and strongly       | The U.S. Episcopalian Church passed a 1982 resolution saying “All Christians are encouraged to become organ, blood and tissue donors as part of their ministry to others in the name of Christ, who gave His life that we may have life in its fullness.”
|                                 | encouraged.                                                                     | The Church of England has declared organ donation to be “a Christian duty.”                                                                          |
| Baptist                         | No official church policy; typically cited as a personal choice.                 | The Southern Baptist Convention passed a motion in 1988 “encouraging physicians to request organ donation in appropriate circumstances and to encourage voluntarism regarding organ donations in the spirit of stewardship, compassion for the needs of others and |

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<table>
<thead>
<tr>
<th>Religion</th>
<th>Position</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brethren (Anabaptist, Schwarzenau Brethren)</td>
<td>No commonly stated position; typically cited as a personal choice.</td>
<td>“There is a consensus among the National Fellowship of Grace Brethren that organ and tissue donation and transplantation is a charitable act so long as it does not impede the life or hasten the death of the donor or does not come from an unborn child” – Pastor Mike Smith</td>
</tr>
<tr>
<td>Buddhism</td>
<td>Tissue donation is a matter of individual conscience, although acts of compassion and sacrifice are lauded by Buddhists.</td>
<td>&quot;We honor those people who donate their bodies and organs to the advancement of medical science and to saving lives.&quot; - Reverend Gyomay Masao, president and founder of the Buddhist Temple of Chicago</td>
</tr>
<tr>
<td>Catholicism</td>
<td>Organ donation is viewed as a spiritually acceptable practice and strongly encouraged. The Vatican has stated that organ transplantation is morally and ethically acceptable. The only concern is that no life is taken prematurely to provide a donation. The Compendium of the Catechism of the Catholic Church states “[t]he transplant of organs is morally acceptable with the consent of the donor and without excessive risks to him or her. Before allowing the noble act of organ donation after death, one must verify...”</td>
<td>&quot;We encourage donation as an act of charity. It is something good that can result from tragedy and a way for families to find comfort by helping others.&quot; - Father Leroy Wickowski, Director of the Office of Health Affairs of the Archdiocese of Chicago. &quot;The Catholic Church would promote the fact that there is a need for organ donors and that Christians should accept this as a 'challenge to their generosity and fraternal love' so long as ethical principles are followed.” – Pope John Paul II</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;The act of love, which is expressed with the gift of one's own vital organs, is a genuine testament of charity that knows how to look beyond death so that life always wins.&quot;</td>
</tr>
</tbody>
</table>
### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

<table>
<thead>
<tr>
<th>Religion</th>
<th>Statement</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Church of Jesus Christ and Latter-Day Saints (Mormon)</strong></td>
<td>The church has taken no official position on organ transplants but does view it as a spiritually acceptable practice. The spiritual concern about the state of the body upon resurrection is answered clerically by “every limb and joint shall be restored to its body, yea, even a hair of the head shall not be lost.” From Alma 40:23</td>
<td>&quot;Whether an individual chooses to will his own bodily organs or authorizes the transplant of organs from a deceased family member is a decision for the individual or the deceased member's family. The decision to receive a donated organ should be made with competent medical counsel and confirmation through prayer&quot; - General Handbook of Instructions, 11-6</td>
</tr>
<tr>
<td><strong>Christian Church (Disciples of Christ)</strong></td>
<td>Organ donation is viewed as spiritually acceptable and strongly encouraged. The official position is the “[humans] were created for God’s glory and for sharing God’s love”</td>
<td>In 1985 the General Assembly adopted a resolution encourages &quot;members of the Christian Church (Disciples of Christ) to enroll as organ donors and prayerfully support those who have received an organ transplant.&quot;</td>
</tr>
<tr>
<td><strong>Christian Science</strong></td>
<td>Although the church has no formal position on organ donation, the church shuns most modern medical practice,</td>
<td>“Christian Scientists normally rely on spiritual instead of medical means of healing” - First Church of Christ</td>
</tr>
</tbody>
</table>

- Pope Benedict XVI

That the donor is truly dead.”

The recipient should be aware of the value of this gesture that one receives, of a gift that goes beyond the therapeutic benefit. What they receive is a testament of love, and it should give rise to a response equally generous, and in this way grows the culture of gift and gratitude.”

- Pope Benedict XVI
<table>
<thead>
<tr>
<th>Religions</th>
<th>Philosophies</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraging members to focus on prayer to cure ailments. It is likely that organ transplantation would be discouraged similarly to chemotherapy and other conventional surgeries.</td>
<td>Scientist in Boston</td>
<td></td>
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<tr>
<td>Confucianism</td>
<td>Prohibited from any form of damage to the body, as Confucian teaching states that the “body, hair and skin are gifts from parents, let no one damage them”. As respect for parents (“filial piety”) is seen as the foundation of Jen (humaneness), organ and tissue donation are precluded.</td>
<td>N/A</td>
</tr>
<tr>
<td>Eastern Orthodox (Greek Orthodox)</td>
<td>Organ donation is viewed as a spiritually acceptable practice.</td>
<td>&quot;The Greek Orthodox Church is not opposed to organ donation as long as the organs and tissue in questions are used to better human life, i.e., for transplantation or for research that will lead to improvements in the treatment and prevention of disease.&quot; - Reverend Dr. Milton Efthimiou, Director of the Department of Church and Society for the Greek Orthodox Church of North and South America</td>
</tr>
<tr>
<td>Hinduism</td>
<td>There are no teachings which preclude organ donation. See the Bhagavad Gita, Chapter 2:25 “...it is said that the</td>
<td>&quot;Hindu mythology has stories in which the parts of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion&quot;</td>
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### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

<table>
<thead>
<tr>
<th>Religion</th>
<th>Quote</th>
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<tbody>
<tr>
<td>Hindu</td>
<td>&quot;It is commonly cited as a personal decision. Strongly encouraged in the Laws of Manu “Of all the things that it is possible to donate, to donate your own body is infinitely more worthwhile.” - H. L. Trivedi, spokesman, the Hindu Temple Society of North America</td>
</tr>
<tr>
<td>Islam</td>
<td>&quot;There are no teachings which preclude organ donation. It is generally encouraged as most scholars state “the religion of Islam believes in the principle of saving human lives”. Qur’an 5:32 “…and if anyone saved a life, it would be as if he saved the life of the whole people.” It is important that clinical death be assured prior to donation and that organs are not sold nor placed in a bank. &quot;The majority of the Muslim scholars belonging to various schools of Islamic law have invoked the principle of priority of saving human life and have permitted the organ transplant as a necessity to procure that noble end.” - A. Sachedina, Islamic Views on Organ Transplantation</td>
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"I can truly say that organ donation provides the gift of life for patients with chronic kidney disease and often eliminates the need for dialysis. I am glad to know that there are no barriers to organ donation in our Hindu scriptures. My family and I have consented to be organ donors. Let us all join in this noble cause.” - Dr. Shiv Jindal, President of the Hindu Temple of Ottawa-Carleton, Former director of kidney transplants, Ottawa Civic Hospital

“Muslims must not be afraid of consenting to donate or feel that they will not be rewarded by Allah for doing this act of organ donation. This intention to save a human life is well founded in the Sharia and this act of kindness is a true sadaqa jariya (perpetual charity), the rewards for
### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

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<tr>
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<th>Philosophy</th>
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<tr>
<td><strong>Jehovah’s Witness</strong></td>
<td>Although not officially prohibited, the preclusion of blood transfusions means that a compliant organ donation must have the donor organ washed of all blood, which is practically impossible in most cases. The donation is theoretically acceptable, but members have been known to be expelled from the church for participating in any form of blood transfusion. “Jehovah’s Witnesses believe donation is a matter of individual decision” – Watch Tower Society</td>
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</table>
| **Judaism** | Organ donation is viewed as spiritually acceptable and strongly encouraged by all four branches: Orthodox, Conservative, Reform and Reconstructionist. The Rabbinical Council of America, the Orthodox governing body, announced that organ donations are acceptable, often to the point of being required, from brain-dead patients. "If one is in the position to donate an organ to save another's life, it's obligatory to do so, even if the donor never knows who the beneficiary will be. The basic principle of Jewish ethics - ‘the infinite worth of the human being’ - also includes donation of corneas, since eyesight restoration is considered a life-saving operation." - Rabbi Moses Tendler, Chairman of the Bioethics Commission of the Rabbinical Council of America "Judaic Responsa materials provide a positive approach and by and large the North American Reform Jewish
### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

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<tbody>
<tr>
<td>Lutheran</td>
<td>Organ donation is viewed as spiritually acceptable and strongly encouraged and the church “[calls] on members to consider donating organs and to make any necessary family and legal arrangements, including the use of a signed donor card.”</td>
<td>“We need to promote it as a religious fulfillment, as a religious imperative, as a religious obligation, as something we should be doing—to get away from this, ‘Aw, it’s OK,’ It’s the right thing to do. It’s a life-saving thing to do.” - Rabbi Reuven Bulka, chairman of the board of Ontario’s Trillium Gift of Life Network</td>
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<tr>
<td>Mennonites</td>
<td>No official church policy; typically cited as a personal choice.</td>
<td>N/A</td>
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<tr>
<td>Moravian</td>
<td>No official church policy; typically cited as a personal choice.</td>
<td>&quot;There is nothing in our doctrine or policy that would prevent a Moravian pastor from assisting a family in making a decision to donate or not to donate an organ.&quot; - Robert E. Sawyer, President, Provincial Elders</td>
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### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

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<tr>
<th>Religion</th>
<th>Official Policy</th>
<th>Notable Institutions/Remarks</th>
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<tbody>
<tr>
<td><strong>Pentecostal</strong></td>
<td>No official church policy; typically cited as a personal choice.</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Presbyterian</strong></td>
<td>No official church policy; typically cited as a personal choice.</td>
<td>N/A</td>
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<tr>
<td><strong>Seventh-Day Adventist</strong></td>
<td>Organ donation is viewed as a spiritually acceptable practice and strongly encouraged. The Seventh-Day Adventists are unique in that the church operates several medical colleges around the world, all of which promote advances to medical care.</td>
<td>Loma Linda University in California has a teaching hospital which specializes in pediatric cardiac transplants.</td>
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<td><strong>Shinto</strong></td>
<td>Organ donation is not officially forbidden, but a dead body is believed to be impure and dangerous. Any “defiling” of a corpse is believed to bring bad luck and damage the relationship between the spirit and those who bereave it (itai).</td>
<td>&quot;In folk belief context, injuring a dead body is a serious crime . . .To this day it is difficult to obtain consent from bereaved families for organ donation or dissection for medical education or pathological anatomy . . . the Japanese regard them all in the sense of injuring a dead body.&quot; - E. Namihira, Shinto Concept Concerning the Dead Human Body</td>
</tr>
<tr>
<td><strong>Sikhism</strong></td>
<td>Support organ donation and positive attitude towards donation and transplantation. Teachings place</td>
<td>&quot;The Sikh religion teaches that life continues after death in the soul, and not the physical body. The last act of giving and helping others through organ donation is</td>
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### APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

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<tr>
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<th>Organ Donation Policy</th>
<th>Notes</th>
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<tr>
<td>Sikhism</td>
<td>Emphasis on selflessness and service to others. The Guru Granth Sahib States &quot;Where self exists, there is no God Where God exists, there is no self.&quot; Cremation is very common among Sikhs and they believe in a continuous cycle of rebirth, which leads to few objections to organ removal post-mortem.</td>
<td>Both consistent with and in the spirit of Sikh teachings.” - Dr. Indarjit Singh OBE, Director of the Network of Sikh Organizations UK (Endorsed by Sikh Authorities in Amritsar, Punjab)</td>
</tr>
<tr>
<td>Society of Friends (Quaker)</td>
<td>No official church policy; typically cited as a personal choice.</td>
<td>N/A</td>
</tr>
<tr>
<td>Taoism</td>
<td>No specific restriction against organ donation.</td>
<td>N/A</td>
</tr>
<tr>
<td>United Church of Canada</td>
<td>Organ donation is viewed as a spiritually acceptable practice and strongly encouraged. The church “actively solicit[s] participation in the organ donor registry or card program at the congregational level.”</td>
<td>The church did a background paper and policy brief on Animal-to-Human Transplants where they advocated “encourag[ing] the study of changes to the current legislative framework for organ donations that might further facilitate organ and tissue donation.”</td>
</tr>
<tr>
<td>United Church of Christ</td>
<td>Organ donation is viewed as a spiritually acceptable practice and strongly encouraged.</td>
<td>&quot;United Church of Christ people, churches and agencies are extremely and overwhelmingly supportive of organ sharing. The General Synod has never spoken to this issue because, in general, the Synod speaks on more</td>
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APPENDIX: RELIGIONS AND ORGAN DONATION PHILOSOPHIES

<table>
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<tr>
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<th>Position on Organ Donation</th>
<th>Source</th>
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<tbody>
<tr>
<td>World Assemblies of God Fellowship</td>
<td>No official church policy, although informally encouraged in most denominations.</td>
<td>N/A</td>
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controversial issues, and there is no controversy about organ sharing, just as there is no controversy about blood donation in the denomination. While the General Synod has never spoken about blood donation, blood donation rooms have been set up at several General Synods. Similarly, any organized effort to get the General Synod delegates or individual churches to sign organ donation cards would meet with generally positive responses." - Reverend Jay Lintner, Director, Washington Office of the United Church of Christ Office for Church in Society