DEScribing and Assessing the Views of Transplant Professionals in Ontario About Directed Organ Donations from Deceased Donors: A Qualitative Study

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science

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ABSTRACT

In Ontario, the organs of deceased donors are usually allocated to those recipients who are ranked highest on the province’s waiting list for transplant surgery. However, on rare occasion, a donor, or the donor’s family, will request that an organ be given to a designated recipient or designated group of recipients. The ethical acceptability of these so-called “directed donations” of organs from deceased donors is debated in the transplant literature. The purpose of this study was to elicit the views of a group of transplant professionals in Ontario on the question, “Under what circumstances, if any, should a donor or the donor’s family be allowed to choose the recipient of the organ?” Qualitative in-depth interviews were conducted with 14 Ontario transplant professionals from a range of clinical disciplines. An analysis of these interviews revealed several practical and ethical considerations that the transplant professionals believed to be important in assessing the acceptability of directed donations.
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CHAPTER 1 – INTRODUCTION

In this chapter, I identify the purpose and objectives of this study, and provide relevant background information for an understanding of directed organ donations from deceased donors in Ontario. I also explain the practical and ethical significance of this study, as well as outline the primary research questions that guided it.

Purpose of this study

In Ontario, Trillium Gift of Life Network (“Trillium”), the province’s central tissue and organ donation agency, allocates the organs of deceased donors to those recipients who are ranked highest on the province’s waiting list for transplant surgery. However, on rare occasion, a donor or the donor’s family will request or insist that an organ be given to a designated recipient or a member of a designated group of recipients. The ethical acceptability of these so-called “directed donations” of organs from deceased donors is debated in the transplant literature. In Ontario, there is currently no official policy to govern directed donations. Given the agency’s legislated mandate to ensure that organs are fairly and ethically allocated (1), Trillium has a continuing interest in considering what factors should be taken into account in responding to directed donations. The purpose of this study was to elicit the views of a group of transplant professionals in Ontario on the question, “Under what circumstances, if any, should a donor or the donor’s family be allowed to choose the recipient of the organ?” Three related objectives followed from the purpose of this study:

1. To explore and describe in detail the views of a group of Ontario transplant professionals on the acceptability of directed donations.
2. To review and synthesize the literature on directed donations from *deceased* donors.

3. To compare and contrast the views of authors in the literature on directed donations and those of the transplant professionals in this study.

**Background**

To appreciate the significance of directed donations in Ontario, it is important to understand generally how deceased organ donation and transplantation function in the province. Under Canada’s Constitution, the delivery of medical care, including organ donation and transplantation, is solely the responsibility of each individual province and territory. In keeping with this, there is no national organ transplant authority in Canada to influence provincial and territorial policies and practices on organ donation and transplantation. In 2001, the Ontario government established the Trillium Gift of Life Network to control and regulate *deceased* organ donation in the province.¹ Trillium’s top priorities are to “significantly increase organ and tissue donation across the province and to improve related processes and functions” (2).

The *Trillium Gift of Life Network Act* (the “TGLN Act”) is currently the legislation governing organ and tissue donation in Ontario (1). Under the TGLN Act, Trillium has the legal authority and responsibility to manage the procurement and distribution of organs from deceased donors (1). This includes the procurement and distribution of kidneys, livers, hearts, lungs, pancreases, small bowels and stomachs, any or all of

¹ In Ontario and the rest of Canada *living* organ donation is governed by the policies and practices established by individual transplant centres at hospitals.
which can be donated by a single deceased donor. As stated on Trillium’s website, the TGLN Act requires the agency to “establish and manage waiting lists for organ and tissue transplants and establish and manage a system of fair allocation” [emphasis added] (2). Under current procedures, Trillium allocates different types of organs according to different criteria, but, in general, organs are allocated based on an acceptable balance between two general ethical principles: medical utility and equity.

On the one hand, medical utility requires that organs be given to recipients who will receive the greatest amount of medical benefit from the transplant surgery. In assessing medical utility the degree of biological compatibility between the donor and the recipient is the most important factor, because a very close biological match will increase the survival of the organ. Specifically, Trillium matches the tissue type and blood type of the donor to that of the recipient in order to maximize the overall success of the transplant operation and make the best use of the organ. Although this biological matching of the donor and the recipient is done for each type of organ, Trillium also weighs additional factors, grounded in medical utility, in distributing certain types of organs. With kidneys, for example, the organs of younger donors, which typically last longer than the organs of older donors, are usually given to younger recipients in order to maximize the life of the organs.

On the other hand, equity – which is based on respect for the equal inherent moral worth of each patient – requires that patients who are in the greatest need of an organ be given priority. This criterion applies primarily to patients in need of livers, hearts, and lungs, without which they face certain death. If two of these patients are in equal need,
priority will be given to the patient who has waited the longest for an organ, another
criterion grounded in equity.\textsuperscript{2} For patients in need of a kidney, time on the waiting list is
normally the principal deciding factor, because, unlike patients needing the organs listed
above, kidney patients can usually stay alive for several years through continued
dialysis. To be sure, a patient’s life-expectancy decreases with prolonged dialysis and, if
his or her condition should worsen to the point of requiring an immediate transplant, he
or she will be given priority.

Medical utility and equity inevitably require trade-offs (3). In some instances, an organ
will be given to a recipient who is in critical need of a transplant (e.g., a liver transplant)
but who may not be the best biological match with the donor compared to other patients
in more stable condition. Or, in other instances, an organ will be given to a well-matched
recipient who needs the organ less quickly than that of a poorly matched recipient,
because the latter may not receive much benefit at all from the transplant.

The aims of the allocation system are to be impartial and objective. In accordance with
these aims, each allocation decision must conform with the various criteria outlined
above, including others not mentioned, which have been scrutinized and agreed on in
advance of such decisions. This standardized allocation process acts as a safeguard
against arbitrary ad hoc considerations or biases in allocation decisions.

\textsuperscript{2} It is worth mentioning that medical utility and equity are ambiguous concepts, and that each
can be defined and calculated in different ways. Different interpretations of medical utility and
equity may point to different relevant factors in allocating organs, and different weights to be
assigned to such factors. For a detailed discussion of the problems in defining and calculating
medical utility and equity see reference (3), chapter 19.
The chronic shortage of organs in Ontario underscores the importance of Trillium’s responsibility to ensure that organs are fairly allocated. At present, about 1,700 patients are waiting for transplant surgery in Ontario, and on average one patient dies waiting every three days (2). The scarcity of organs also reinforces the importance of Trillium’s mandate to increase the general supply. Accordingly, the agency has taken various steps to raise public awareness of the organ shortage, and to encourage prospective donors to notify their families of their preference to donate (4). In addition, legislation has been enacted to increase hospitals’ reporting of certain deaths to Trillium, and in-hospital transplant coordinators are being trained on how to most effectively request donations from the families of deceased or dying patients (4). Despite these and many other efforts, the demand for organs far outstrips supply.

Trillium’s interest in obtaining organs and its duty to allocate them in an ethically acceptable manner appear to clash when it is confronted with the dilemma of whether to accept a directed donation. In simple terms, accepting the donation would benefit the designated recipient – and all those ranked below the designated recipient who advance on the waiting list – but would require deviating from the standard allocation criteria. That is, the donation would allow a patient of lower priority on the waiting list to bypass other patients. In more philosophical terms, the problem can be understood as a conflict between the freedom, or autonomy, of a donor or the donor’s family to direct

3 Ontario and other Canadian provinces and territories use an “opt-in” donation model whereby a person must give consent to the removal of his or her organs, after death, for the purpose of donation. If the deceased’s wishes are unknown, the family is asked to give consent on his or her behalf. In Ontario, even if the deceased had explicitly registered a wish to donate, out of respect for the grieving family, they are routinely asked for permission to proceed in accordance with the deceased’s wish. Trillium encourages people to inform their families about their wish to donate organs so that the families will be more inclined to support the wish of their deceased relative and to allow the donation to proceed.
organs based on personal preferences and Trillium’s obligation to distribute organs based on societal values of medical utility and equity (5). 4

The baby Kaylee case

In April of 2009, during the final stages of this research, a controversial case of organ donation unfolded in Toronto. This case captured international attention and raised questions by the public and media about the ethics of directed donations (6,7).

This case centred around two terminally-ill infants: Kaylee Wallace, who was born with a severe form of Joubert syndrome, a malformation of the brain that was believed to make her survival impossible, and Lillian O’Connor, who was born with truncus arteriosus, a congenital heart defect that allowed her just weeks to live. After reading about Lillian’s critical need for a heart transplant in the Toronto Sun, Kaylee’s parents purposely sought out Lillian’s parents at the Hospital for Sick Children, where both infants remained under medical surveillance, and offered to donate their child’s heart to Lillian once Kaylee was removed from a life-sustaining ventilator and pronounced dead on the basis of cardiac criteria. 5 The Hospital for Sick Children initially refused the donation

4 I have characterized the central tension in directed donations as that between personal preferences and societal values in the fair distribution of organs. It is important, also, to recognize the tension between the distribution of organs and their acquisition, which I mentioned previously. That is, Trillium must deal not only with the issue of fair distribution, but also, with the issue of acquisition, which are closely connected and intertwined.

5 Most donations in Ontario are from patients who are pronounced brain dead, but Kaylee was being considered for donation after cardiac death, a type of donation that was re-introduced in Ontario in 2006. Donation after cardiac death is only considered following a prior and independent decision by the patient or his or her family to withdraw life support (2). Interestingly, in an article by Ankeny on directed donations, she alluded to the possibility that the practice of donation after cardiac death could lead to an increase in requests to direct organs, because
because they thought that once Kaylee was taken off a ventilator, she would not die
within the two-hour national guideline that would ensure her heart would still be viable
for transplantation. The next day, a subsequent assessment of Kaylee revealed that
she had sufficient possibility of dying to warrant attempting a donation after cardiac
death, and so the hospital agreed to facilitate the donation.

This case sparked controversy over Kaylee’s parents’ selection of Lillian as the
recipient, notwithstanding that Lillian happened to be the most urgently in need and
compatible paediatric heart patient on the waiting list. The intense media coverage of
the case (aided by both parents’ willingness to hold media conferences) and that both
parents had met and visited the other parents’ daughter, made it impossible to conceal
the identities of the donor and the recipient, which is required by law in Ontario.

In the end, the transplant did not occur. Kaylee remained alive for hours after the
respirator was removed, thus preventing physicians from carrying out the operation. She
was eventually put back on the breathing machine and, at the completion of this thesis,
was still alive.

The baby Kaylee case demonstrates one of the ways in which directed donations may
occur. It is significant in that it was the first and only case in Ontario involving a

6 Given that Kaylee was being considered for donation after cardiac death, the precise time at
which Kaylee was pronounced dead was a critical factor. The longer she would remain alive
after life support was removed, the longer her heart would be without the flow of blood or
oxygen, and the more her heart would be damaged as a result.
(potential) directed donation from a deceased donor to have entered the public domain. Because it prompted numerous comments and questions from the media and the public about the ethics of directed donations, it was possible to gain at least some insight into some Ontarian’s attitudes about directed donations. The evidence of such attitudes is far too limited to draw any major conclusions about their nature, but it is at least apparent the public considers directed donations to be an important issue.

Significance of this study

Despite the rare occurrences of directed donations in Ontario, they can and do arise, and their frequency may increase with, for example, success in raising public awareness of organ donation, and greater use of advanced care planning to guide decisions at patients’ end of life. As the agency responsible for the fair distribution of organs in Ontario, it is a matter of great ethical, practical, and political importance that Trillium continues to consider carefully what factors should be weighed in responding to directed donations. Accordingly, I set out to explore the views of a sample of Ontario transplant professionals – an important stakeholder group – on the acceptability of directed donations primarily with the hope that such information might inform Trillium’s consideration of such factors.

To date, to the best of my knowledge, no research has been conducted on the views of transplant professionals in Ontario, or elsewhere in Canada, on directed donations. Nor have the views of any other important Ontario stakeholder groups been systematically studied, for example, policy-makers, the general public, other health care professionals (especially those in the critical care community), as well as potential recipients and their
families. Based on the importance of stakeholder engagement in informing health policies and practices from a deliberative democracy standpoint, I believe that it is important to elicit – and that we can learn from – the perspectives of each of the above stakeholder groups on directed donations. A liberal political theory, deliberative democracy supports an inclusive approach to policy-making in which the diverse values, interests, and concerns among various groups in society about public problems are weighed in an effort to find mutually acceptable solutions.

My decision to explore the views only of transplant professionals reflects practical research constraints such as limited time and fixed resources. As such, this study was intended to be a first step toward addressing the larger information gap identified above. The main reason for choosing to focus on the views of transplant professionals was their specialized knowledge about organ donation and transplantation in general and organ allocation in particular. Transplant professionals can be considered “key informants” on the subject. A few of the transplant professionals in this study had even dealt personally with requests from families to direct organs and could offer valuable insights based on their experiences.

Providing Trillium with information for use in further considering how best to respond to directed donations was not the only aim of this study. Another important aim was to allow members of the broader transplant community, in Canada and abroad, to learn what some of their colleagues in Ontario had to say about the acceptability of directed donations.

7 “Key informants” are people who are particularly knowledgeable about the topic being studied and are able to articulate such knowledge (43).
donations. Indeed, the issue is debated internationally and, in some countries, transplant authorities, like Trillium, have been forced to deal with the practical and ethical challenges presented by directed donations.

In United States, the *Uniform Anatomical Gift Act* (9) gives a donor or the donor’s family legal authority to direct an organ to a particular designated recipient. Most of the roughly 100 directed donations that occur every year in the United States are from donors who are related to the recipient or know the recipient personally (10). However, directed donations to recipients who are neither related nor known personally to the donor have sparked much controversy and ethical debate (11). Just recently, in May of 2009, Natalie Cole, a famous American singer who had disclosed her need of a kidney on *Larry King Live*, received a kidney through a directed donation from a deceased fan, which provoked concerns over the fairness of directed donations resulting from public solicitation, as well as giving celebrities priority for organs (12). Also, in the United Kingdom, directed donations became an issue of great importance in the wake of public outrage over a transplant team’s decision to accept organs that the donor’s family had stipulated could only be given to patients of a specified race (13).

The issue of directed donations raises many questions of relevance to the broader debate about the ethics of organ donation and allocation, for example, “What are the appropriate limits of personal autonomy?”, “What rights should people have, after death, 

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8 Under Section 11 of this law a donor is permitted to designate any of various potential recipients, including “a hospital; accredited medical school, dental school, college, or university; organ procurement organization; or other appropriate person, for research or education...[or] an individual designated by the person making the anatomical gift if the individual is the recipient of the part” [emphasis added] (9).
over the use of their body parts?”, “What are acceptable motives for the donation of organs?”, “Should organs be considered personal property or societal resources?”, “Is a strictly objective and impartial organ allocation system ethically justifiable?”, “How much weight should be given to the interests of deceased persons, or those of their family members?” This study’s exploration and description of the views of a sample of Ontario transplant professionals about directed donations provided insight into these and other related ethical questions. As such, it was hopefully a contribution to our knowledge and understanding of organ donation and allocation more generally.

Research questions

The primary research question that I was interested in exploring in this study was, “From the perspectives of a group of Ontario transplant professionals, when, if ever, should a donor or the donor’s family be allowed to choose the recipient of the organ?” In exploring this question, I attempted to ascertain the rationales, beliefs and assumptions behind the transplant professionals’ views on directed donations. I also set out to research a complementary question, “What do authors in the literature think about the acceptability of directed donations?”, because examining such authors’ views was necessary to carry out an in-depth analysis of the related question, “How are the views of the authors in the literature similar to and different from the views of the transplant professionals?”
CHAPTER 2 – LITERATURE REVIEW

In this chapter, I review the published literature on directed donations from deceased donors with two primary aims. First, I hope to show the ways in which the literature informed this study and its design. Second, this literature review provides an overview of the dominant views among authors on directed donations. This is important in helping to understand and contextualize the participants’ responses, which I discuss below in the “Results” and “Discussion” chapters.

The debate about directed donations is multifaceted, at times philosophical, and characterized by considerable differences of opinion. To offer greater clarity, I have classified the dominant views into those in favour or against directed donations. I have also presented authors’ counter-arguments to some of the dominant views.

Gap in the literature

Most of the literature on directed donations from deceased donors consists of various authors’ considered views on the issue, which I discuss below. The lack of empirical social research on directed donations has left a wide knowledge gap. As I mentioned, a principal reason for eliciting the views of transplant professionals in Ontario was that their views about directed donations were unknown.

The only empirical social research on directed donations from deceased donors is an opinion survey, conducted in 2008, that is representative of the United Kingdom public.

9 References to the “literature” are to materials written and/or published on the topic of directed donations from deceased donors. References to the “authors” are to ethicists, professors, transplant professionals, transplant organizations, and so on, who wrote and/or published materials contained in the literature.
The survey sought opinions about “conditional donations”, which are a subtype of directed donations in which the donor agrees to donate only if the organ is given to the designated recipient. In the survey, 30% of the respondents said that conditional donations were “fairly acceptable”, although certain types of conditions evoked different levels of acceptance. A large majority of respondents (79%) stated that it was “not very or not at all acceptable” for a donor to direct an organ to a recipient based on his or her race; 59% stated that it was “very or fairly acceptable” to give children priority; 39% said that it was “very or fairly acceptable” to restrict an organ from going to recipients with alcohol-induced liver disease; and 51% stated that it was “not very or not acceptable at all” to designate a family member.

A closer examination of this survey’s methodology helps to show why I used qualitative in-depth interviews rather than a statistically-oriented survey to obtain the views of transplant professionals. First, this survey was based on a questionnaire that contained a limited number of closed-ended questions and fixed response categories. This made it impossible to understand why the respondents felt the way they did about conditional donations. That is, we cannot determine whether the public’s views were based on, for example, inaccurate information, misunderstanding, or unreasonable moral assumptions. Second, the survey sought respondents’ views about conditional donations. Hilhorst et al. identified very similar weaknesses in a survey, conducted in the United States in 2003, that used a statistically-oriented questionnaire to gauge the public’s opinions about whether unrelated living donors should be able to choose their recipients. The authors concluded that in-depth interviews would be a more appropriate method for exploring people’s opinions about such a morally complex subject, because interviews make it possible to identify the complex beliefs and assumptions behind the respondents’ opinions. See: Hilhorst MT, Kranenburg LW, Zuidema W, Weimar W, Ijzermans JNM, Passchier J, et al. Altruistic living kidney donation challenges psychosocial research and policy: a response to previous articles. Transplantation 2005;79(11):1470-1474. Hilhorst et al.’s conclusion reinforced my decision to conduct in-depth interviews with transplant professionals. For a discussion of the survey’s
donations with respect to a limited range of recipient candidates (e.g., children, a family member). This constrained the ability to discover the public’s views about conditional donations that involved other recipient candidates. Would the respondents, for instance, who believed it was acceptable to donate to a family member, have also supported donations to a close friend?

Real-life examples of directed donations and their three abstract categories

An examination of real-life cases of directed donations such as the baby Kaylee case above helps to illuminate the different dimensions of such donations. In 2008, *Transplantation* (the official journal of The Transplantation Society, an international body that offers guidance on clinical and ethical transplant practice) presented a special forum on directed donations, featuring summaries of six relatively recent cases that occurred in the United Kingdom (15). I shall paraphrase three of them below:

1. In 2006, a middle-aged man suffered a spontaneous intra-cerebral bleed and was declared brain dead. His 9-month-old daughter, who had developed a fatal liver condition, had been on the transplant waiting list for a liver. The family agreed to donate on the condition that a segment of the liver be given to the daughter (it is possible to split an adult-sized liver and implant part of it in a child). Directed donations were prohibited under a United Kingdom national policy, but after consultation with representatives at United Kingdom Transplant and the Department of Health, the donation was accepted because they believed that the public would support it.

2. In 1999, the parents of a 3-year-old child with chronic liver disease issued a public appeal on national television for an organ donor. A couple of days later a 14-year-old boy was struck by a car and suffered a fatal head injury. The boy’s parents (along with their son) had been emotionally touched by the public appeal, and requested that their son’s liver be implanted in the child. After the parents were informed that their request could not be accepted...
because directed donations were prohibited under a national policy, they agreed to donate their son’s organs based on the standard allocation criteria.

3. In 1999, a young white British male was in a car accident and suffered a severe head injury. He was declared brain dead by physicians at the hospital. He carried a donor card expressing his wish to donate multiple organs. The family stipulated that their deceased relative’s organs be given to white recipients only, claiming that was what their relative had wanted. The donation was accepted. A consultant involved in the decision claimed that the recipient of the liver would have died within 24 hours without transplant surgery. Subsequently, as a result of public indignation, the British government instituted the national policy above banning all directed donations (13).

These cases offer concrete examples of three general categories of directed donations. The first case is an example of donations in which the designated recipient is genetically or emotionally related to the donor, for example, a family member or a friend. The second case is illustrative of donations in which the designated recipient is not known personally, but becomes identified to the donor through public information. Usually, the designated recipient’s need of an organ is disclosed in the print or electronic media, or by word-of-mouth. The third case is an example of donations in which the designated recipient is a member of a particular and identifiable group of recipients. The group may be identified by age, gender, ethnicity, religious faith, cause of illness, or other characteristics. The donor may attempt to prioritize a specific group to receive organs, or to restrict a particular group from receiving them.

Another case outlined by Transplantation’s special forum involved a family who agreed to donate their relative’s organs only if these organs were withheld from alcoholic patients (15). A radio host had contacted the United Kingdom Department of Health and

11 These three general categories of directed donations are closely based on those outlined by Fox (17). The author offered interesting examples of real-life cases of directed donations that occurred in the United States to illustrate the three categories.
questioned why the conditional donation was rejected considering that patients with alcoholic cirrhosis had brought the disease upon themselves. As well, in another case, an ethical question was raised as to whether it was acceptable to prioritize children in accordance with the donor’s wishes (15).

I used the cases described by the special forum as a starting point for creating six different hypothetical scenarios involving directed donations (outlined in the “Methods” chapter), which I presented to the transplant professionals in this study as a basis for discussion during the interviews. By asking the transplant professionals questions about each of the hypothetical scenarios, I aimed to elicit their views about directed donations involving typical designated recipients within each of the three abstract categories above.

Dominant views in favour of directed donations from deceased donors

1. Allowing directed donations would respect the personal preferences of a donor or the donor’s family toward recipients whom they care about.

A common view among authors in the literature, although not always explicitly articulated, was that having a familial relationship with the designated recipient is justification for allowing the donor or the donor’s family to direct the donation of the organ (11,16-25). According to Kluge, “Family ties…are uniquely privileging and identifying, and organ donation occurring within the immediate family context does not violate the equality-and-justice condition” (p.12) (18). He asserted that allowing donations to a family member would honour the importance society places on the family unit.
There was also much support among authors for allowing a donor, or the donor’s family, to designate a recipient with whom they have an emotional or personal relationship, for example, a friend (16,17,19,21-23,26). For instance, The Transplant Society’s official statement on directed donations stated as one of its principal conditions for allowing directed donations that the designated recipient be “an individual with a personal or long-standing emotional relationship to the donor or donor family” (p.1539) (21).

Fox argued that a recipient who has a personal relationship with the donor, or the donor’s family, has a morally relevant claim on the organ which distinguishes him or her from other recipients (17). He further asserted that the transplant community’s rhetoric of organ donation as a “gift of life” presents a false dichotomy, because donors are forced to grant an anonymous gift to an unidentified recipient who is selected by an impartial algorithm, which is different than standard forms of gift-giving. He argued that, by allowing a donor, or the donor’s family, to direct an organ to a recipient who is known personally, the transplant community would acknowledge the personal and relational significance of the gift exchange (17).

As well, Hilhorst held the view that, in personal relationships, people have morally significant “loyalties and commitments” to each other, which, in turn, justify their “partiality” or partial preferences for one another (p.214) (22). To this author, partiality has special meaning personally and morally and is a central part of our personal moral identities (22). (The basic idea is that we naturally favour, and sometimes even ought to favour, people with whom we share special ties, that is, to whom we have basic loyalties

12 In moral philosophy the term “partiality” is distinguishable from mere bias or prejudice.
and commitments, and whose well-being is of special concern to us.) Hilhorst argued that a donor’s partial preference for a specific potential recipient is an expression of such special felt loyalties and commitments, and, accordingly, warrants moral respect (22).

There was not much support among authors for allowing a donor, or the donor’s family, to direct an organ to a recipient who is not known personally (16-18,20,21,24,26,27). The general opinion was captured particularly well by Ankeny’s argument that a donation to such a recipient does not “have the compensating ethical advantage that the emotionally related case does, because the emotionally related person’s interests and preferences are directly and personally tied to the welfare of the potential recipient” (p.6) (16). Similarly, Fox argued that recipients who are known only publicly do not have a morally relevant claim on the organs that would justify treating them differently than other recipients (17).

Authors generally held the view, explicitly or implicitly, that the personal preferences of a donor, or the donor’s family, toward designated groups of recipients should not be respected (11,16,17,19,24-26). The major objection to group-based donations was based on the view that it is unfair to give patients priority access to organs, or to exclude patients from receiving organs, based upon their membership in a particular group, especially on the basis of age, ethnicity, religious faith, gender, cause of illness, or other characteristics that might be considered discriminatory or prejudicial.
In United States, in 1994, the United Network for Organ Sharing (UNOS) (the national organization in charge of organ donation) publicly declared all group-based donations impermissible (28). The declaration was made as a result of a controversial case in which the family of a reported Ku Klux Klan member, who was shot and killed during an attempted robbery, agreed to donate the relative’s organs on the condition that the organs be given to white people only (29). Rather than lose the organs, the regional Organ Procurement Agency accepted the condition and, as a result, sparked considerable public anger.

Several authors expressed similar disapproval of a non-profit organ donor organization in the United States called LifeSharers (11,30). Its members (more than 11,500) promise to donate organs after they die, but to direct them first to fellow members, if a suitable match can be found, before offering them to non-members (31). The LifeSharers initiative is unique in that it does not identify the recipient group based upon patients’ sociological characteristics, but rather, their membership in the organization – one which purports to increase donation rates by encouraging people to register their commitment to donate organs upon their death (31).

Critics such as Zink, Wertlieb, Catalano, and Marwin argued that LifeSharers disrupts the equitable allocation of organs because it weighs a recipient’s public declaration to donate above his or her need (11). Other criticisms included that access to LifeSharers may be limited for people who lack a proficiency in English, access to computers (most

13 To sidestep UNOS’s prohibition on group-based donations, the members of LifeSharers simply designate a particular member in need, who is identified by the organization. This way, the donation is also legally permitted under the Uniform Anatomical Gift Act, which, as I mentioned, allows a donor to designate a specific recipient.
people gain access through the Internet), and knowledge about the organization, as well as that the organization unfairly overlooks all those who are not members but who have registered their willingness to donate for purely altruistic reasons (30).

On the other hand, Undis, one of the co-founders of the organization, argued that LifeSharers justifiably offers those who are willing to donate organs a better chance to receive them (32). The author stated that the basis on which LifeSharers' discriminates between patients is justified and fair, as opposed to discrimination based on, for example, sex, religion, sexual orientation, and health status, which is unjustifiable and unfair. As well, Hilhorst argued that the success of LifeSharers demonstrates the power of partial loyalties and commitments that people have toward particular groups (23). The author asserted that a donor’s partial preferences toward certain groups should be respected if they are not morally problematic, for example, if they do not imply unfair discrimination or prejudice (22).

There was one relatively minor anomaly to the general opposition to group-based donations. Some authors argued that directed donations to children should be permitted (24,25). Price asserted, for example, that children need organs more than adults do in order to fulfill a minimal lifespan (24). As well, the British Transplant Society argued that because most donors are adults, children have a limited opportunity to receive organs that are an appropriate size and, therefore, privileging children would help redress this disadvantage (20).
2. Allowing directed donations would motivate people to donate and increase donation rates.

Low deceased donation rates have been attributed to the supposition that the average citizen is not easily motivated to donate out of an altruistic concern for the general pool of anonymous recipients (33). Some authors have argued that people are more easily stimulated by targeting their sympathetic concern for the suffering of identifiable recipients (22,33). Thus, McGee wrote, “It is far easier to care for a specific individual than humanity in general” (p.19) (33). As well, drawing an analogy between the donation of organs and other charitable acts, Hilhorst argued that a person’s choice of charity expresses his or her commitment to a particular cause, which fuels motivation (22).

Sade has proposed the Selection of Potential Recipients of Transplants (SPRT) program, in which people would be allowed to designate recipients. He argued that the program would increase donation rates by providing donors or their families “the powerful benefit of memorializing [the donors’] lives by recognizing and honouring their personal values through the choice of organ recipients” (p.439) (34). There is, however, no solid empirical evidence that allowing directed donations would encourage (or discourage) organ donations, a point that some authors have acknowledged (16,34,35).\(^\text{14}\)

Wilkinson argued that it is at least possible to measure the immediate impact of accepting or rejecting a directed donation in individual cases (35). He asserted that a

\(^\text{14}\) Through pilot studies, we may be able to measure the effects of different policies on directed donations. Such studies would help to determine whether the currently theoretical assertion, that freedom with respect to recipient selection would stimulate donations, has any empirical basis.
directed donation should be accepted “if it will save at least one life without reducing anyone’s access to organs” (p.65) (35). He, therefore, concluded that a directed donation should be accepted if the donor’s family will withdraw the organ (or multiple organs) unless it is given to the designated recipient (i.e., if the offer of donation is conditional). It has also been noted that by accepting a directed donation each recipient candidate beneath the designated recipient indirectly benefits by advancing on the waiting list (36).

3. Allowing deceased donors to choose their recipients would be morally consistent with allowing living donors to choose their recipients.

Ankeny pointed out that by allowing living people to donate organs to relatives and friends the transplant community has implicitly endorsed a form of directed donations (16). Similarly, Hilhorst asserted that in standard living donations “an organ is given, if and only if, the specific relative, as indicated, is the recipient” (p.201) (22). The author emphasized that living donations are accepted even though they lead to “unequal opportunities and unequal outcomes”, because not every person is able to find a suitable living donor (p.201) (22). Hilhorst argued that it is inconsistent to maintain two separate allocation systems: one for living donation, predicated on the value of partiality, and one for deceased donation, predicated on the value of impartiality (23). His view was that there is no sound reason for considering a deceased donor’s preferences toward particular recipients to be less morally significant or worthy of respect than a living donor’s preferences toward particular recipients. He argued that the system of “partial ethics” that governs living donations should also govern deceased donations (p.201) (23).
No authors have objected directly to Hilhorst’s view, but some have identified morally relevant differences between living donors and deceased donors that may challenge it. For example, the British Transplant Society argued that a living donor is a conscious being who has the freedom to make decisions that impact him or her personally, including whom to donate organs, but that after death the person is no longer conscious and no longer retains such autonomy (20).15

Dominant views against directed donations from deceased donors

1. Organs are societal resources and therefore should be allocated in the manner that best serves society as a whole.

One of the issues discussed in the literature is whether organs removed for the purpose of transplantation should be considered personal property or societal resources. According to Land, the question of who owns transplantable organs is highly important because authority over their use can be determined based on the answer (37). Cronin and Price asserted that it is commonly stated, as if it were accepted as self-evident, that organs are societal resources to be allocated by transplant authorities on behalf of the state (38). Kluge, however, attempted to demonstrate why organs should be considered societal resources. He held the view that the gift of a donated organ is realized only by

15 Although beyond the scope of this thesis, whether authority over the use of one’s organs should be more limited after death than while alive is a question left for ethicists to answer. On the one hand, the fundamental importance of autonomy is entrenched in the practice of obtaining a person’s consent to the removal of his or her organs, after death, for the purpose of donating them. Further, the practice of leaving a personal estate to a person or other beneficiary by a will is based on respect for the wishes and values of the deceased. On the other hand, should the wishes of a deceased donor be given as much weight as a living donor’s considering that, unlike the latter, the former will not have the opportunity to experience the potential benefits (emotional, social or psychological) of helping the recipient of his or her choice? As well, how much weight should be given to the wishes of the donor’s family, who, unlike their deceased relative, will live to experience the potential benefits of the donation?
through the direct participation of public institutions (e.g., hospitals, the transplant community) (18). Kluge argued that, through public intervention, organs transform from private property as bodily tissue, to societal property after they are donated. He concluded that organs should be allocated in accordance with the societal values of equity and utility, and without regard to the personal preferences of individual donors (except if the designated recipient is a family member, as mentioned above) (18).

Contrary to Kluge’s view, Ankeny argued that public intervention does not transform private property into societal property (16). As an illustration, she pointed out that people bequeath material possessions after death, and even though the practice is institutionalized and legally enforced (i.e., public institutions participate directly), the items remain private property (16).

A view in favour of organs as private property was expressed by Cohen, who, writing in the American context, argued that UNOS has “custody and control of organs subject to the conditions placed upon them by the donors” (p.13) (39). He asserted that UNOS should perform the same duties as a charity trustee, who is obligated to manage the trust assets in the manner agreed to by the settler, or donor (39).16

16 It is important to note that it has not been established in law whether, and to what extent, a person, after death, has a property-based claim on donated organs. According to Nwabueze, in the United States, the longstanding no-property rule in dead bodies was recently challenged in Colavito v. New York Organ Donor Network (2006), when a Court of Appeals (state-level) accepted the possibility of a statute-based property right in a functioning organ. The Court of Appeals’ judgment notwithstanding, Nwabueze stated the property status of organs (donated to designated recipients) has yet to be determined in law. See: Nwabueze RN. Donated organs, property rights and the remedial quagmire. Med Law Rev 2008;16(2):201-224. Further, Glazier and Sasjack noted that most United States courts have refused to accept appeals to property law in cases involving organ transplantation (40). Neither has the status of donated organs been established in United Kingdom law. For a discussion of property rights with respect to deceased directed donations in the United Kingdom, see reference (38).
2. Allowing directed donations that stem from public solicitation for organs would give recipients who are able to advertise their need an unfair advantage to obtain organs.

A major argument against directed donations that result from public appeals for organs (e.g., through newspapers, television, Internet websites) was that not everyone who has a need is able to launch an effective campaign for organs (11,16,18,21,24,27). It was argued that patients with greater resources (11), public relations skills (18), access to media (16,18), or political and social connections (27) would have an unfair advantage to obtain organs. The basic moral assumption behind these arguments was summarized by Ankeny, who argued that patients’ unequal abilities to market their need should not be allowed to result in unequal access to organs (16). The author further argued that “merely coming to care about a potential recipient whom you see night after night on the local news does not count as a morally significant emotional relationship, or to put it in a slightly different way, does not provide grounds for appropriate partiality” (p.6) (16).

Kluge focused his attack specifically on the participation by mainstream media in an organ donation campaign (18). He argued that by targeting a single needy person, the media implies that his or her condition is isolated or unique, which misrepresents the true state of affairs. The author further suggested that the media should present a specific patient in need as only one among other such patients, thereby offering a comparative context in which the public can evaluate the moral significance of the specific patient’s need more accurately (18).
In 2005, in response to growing concerns about the inequity resulting from solicited donations in the United States, the Organ Procurement and Transplantation Network (OPTN) and UNOS issued a national advisory urging Organ Procurement Agencies to reject directed donations from deceased donors that originate through public solicitation and where there is no pre-existing relationship between the donor and recipient (26). The advisory came one year after a controversial case had occurred in Texas in which a middle-aged man (with help from his family) took aggressive steps to advertise his need for a liver. He rented two billboards on busy highways in Oklahoma that read “I NEED A LIVER. PLEASE HELP SAVE MY LIFE”, which referred observers to an Internet website that provided in-depth coverage of his plight (40). A family had been moved by the man’s appeal and was permitted to donate the liver of their deceased relative to him despite the man’s advanced metastatic cancer. He died less than a year later.

3. Allowing directed donations would harm the integrity of the transplant system and decrease donation rates.

Many authors agreed that the public’s trust and confidence in the transplantation system is critical for its overall success (11,16,17,20,21,41,42). According to Caulfield and Reis, an essential feature of such trust and confidence is the public’s perception that the transplant system’s policies and practices are fair (42). One of the concerns raised was that directed donations (particularly those that discriminate based on patients’ group characteristics, or those that result from public solicitation) may undermine the public’s perception of fairness in the allocation of organs. Pennings argued that permitting group-based donations may even reduce the overall number of organ donations if people refuse to support a system that they consider unjust (19). Given the importance
of public trust, The Transplantation Society stated in its official statement on directed donations that “It is thus important that the principles for organ allocation are ethically based, transparent, and broadly accepted in society” (p.1538) (21).

Knowledge of the dominant views in favour and against directed donations, as well as the various counter-arguments to these views, outlined above, helped inform this study’s design. As I explain more thoroughly in the “Methods” chapter, I asked the transplant professionals in this study to respond to various opposing views about directed donations depending on their responses to the hypothetical scenarios – a technique that prompted greater reflection on the subject. As well, I incorporated into the hypothetical scenarios various aspects of the debate on directed donations with which authors appeared to be most concerned, for example, public solicitation, the LifeShares’ initiative, appropriate versus inappropriate partiality, and the different degrees of relatedness between the donor, or the donor’s family, and the recipient.
CHAPTER 3 – METHODS

In this chapter, I provide the rationale for adopting a qualitative approach to inquiry. I also describe the research methods used in this study, including the means by which I selected and recruited participants, as well as the methods of data collection and data analysis.

Qualitative methods

As I said above, I was interested in eliciting the views of the transplant professionals in this study on the question, “Under what circumstances, if any, should a donor or the donor’s family be allowed to choose the recipient of the organ?” Further, I aimed to determine why the transplant professionals felt the way they did about directed donations. For example, if a transplant professional felt it was acceptable to designate a family member but not a patient whose need was disclosed in the media, or believed that donors should never be allowed to designate a particular group of recipients, I attempted to ascertain the reasons, beliefs or assumptions upon which the transplant professional based his or her views.

Given that the purpose of this study was exploratory, the use of qualitative research methods was an appropriate means of investigation. Using in-depth interviews, direct observation, or written documents as the primary sources of data, qualitative methods make it possible to study issues in depth and detail (43). As such, qualitative methods are useful for studying areas of social inquiry about which relatively little is known (44). In contrast to qualitative methods, quantitative methods “use standardized measures so that varying perspectives and experiences of people can be fit into a limited number of
predetermined response categories to which numbers are assigned” (p.14) (43). The advantage of quantitative methods is that it is possible to measure the responses of a large number of people to a limited number of questions, and thus to obtain results that are broad and able to be generalized. Qualitative methods, on the other hand, produce a large volume of detailed responses from a small number of people, and thus increase the depth of understanding about the people or the responses elicited (43).

The data in this study came from in-depth interviews based on semi-structured, open-ended questions about hypothetical scenarios involving different forms of directed donations. To analyse the data, I used some, but not all, of the procedures of a qualitative methodology called “grounded theory” as described by Strauss and Corbin (45). For reasons outlined below in the “Data analysis” section, my goal in using selected grounded theory procedures was not to develop a theory, as would be the aim of researchers who adopt this methodology in its complete form (45). Rather, my goal was to organize the transplant professionals’ responses into well-developed themes (called “categories” in grounded theory research) that accurately depicted what they believed to be most important about various aspects of directed donations.

Selection of participants

This study used a sampling technique called “purposeful sampling”, the logic and power of which, according to Patton, is in selecting information-rich participants who will best illuminate one’s research question (43). I selected participants who were actively and professionally involved in the delivery of clinical organ transplant services and, therefore, who met the definition of “transplant professional” for the purposes of this
The participants were recruited from a large-scale organ transplant centre at a hospital in Ontario, Canada.

To obtain a diversity of perspectives, I selected participants from a variety of clinical disciplines. My sample included four social workers, two surgeons, three medical doctors (who were not surgeons), four registered nurses who were also transplant coordinators, and one spiritual caregiver. The 14 participants included eight women and six men, had an age range of 30-69, and had been involved in transplantation for a range of 3 to 30 years.

The goal of using a small, purposeful sample was to obtain in-depth information about the transplant professionals’ views. This facilitated a deeper understanding about the reasons, beliefs and assumptions behind such views. In qualitative research, the adequacy of a sample size does not depend on the number of participants interviewed, but on the sufficiency and quality of the information elicited (46). I determined that 14 participants constituted an adequate sample size when the information gathered had become saturated, that is, new patterns in the data had ceased to emerge in the final interviews (45).

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17 The sample in this research cannot be confidently generalized to the larger population of transplant professionals in Ontario. Such generalizing would be the aim in quantitative research, which uses a technique called probability sampling to attain a statistical aggregation of the data (43).
Participant recruitment

I was required by the hospital’s Research Ethics Board to enlist the help of a hospital employee (an “on-staff supervisor”) for the purpose of recruiting participants. The on-staff supervisor helped me to generate a list of potential participants from across the clinical disciplines mentioned above. The on-staff supervisor sent a letter of invitation by e-mail to 18 potential participants (Appendix A). The letter stated that the intent of the study was to explore the views of Ontario transplant professionals on the question, “Under what circumstances, if any, should a person, or his or her family, be permitted to direct organs to a particular designated recipient or designated group of recipients?”

The very day the invitation letters were sent, six people contacted me with an interest in participating. Within about two weeks, eight more people had done the same, although some had responded after I had sent a follow up letter to remind them about the study. Participants who were interested in participating were sent a letter of information and consent form that described the research in greater detail (Appendix B), and were then given an opportunity to ask questions. Following this, an interview appointment was arranged. The interviews took place in a private room at a location that was convenient for the participant, usually at the hospital.

18 The on-staff supervisor was also responsible for overseeing the ethical conduct of my study at the hospital. As I will discuss below in the section, “Ethical considerations”, participants were promised that the name of the hospital where they worked would not be identified as an additional measure to safeguard their anonymity. For this reason, I cannot name the on-staff supervisor, or else it would be possible to determine at which hospital the participants worked.
Ethical considerations

Written consent to participate in this study was obtained from the participants at the time of the interview, only after I had reviewed with them the content of the letter of information and consent form. I also addressed the participants’ questions about the purpose of the study, the risks and benefits of participating, the measures taken to safeguard their anonymity, and their rights as a participant.

To protect the participants’ anonymity, their names, the name of the hospital where they worked, and any other details that could identify them were treated as confidential. With the participants’ permission, I audio recorded the interviews. I alone transcribed the audio recordings and, after checking the transcripts for accuracy, immediately destroyed the audio recordings. A unique number code was used in lieu of the participants’ names to identify the interview transcripts. In addition, any data that contained personal information, as well as the interview transcripts, were kept confidential and stored in a secure area. Each participant gave me permission to use anonymous quotations from the interview in this thesis or any publication that might result from this study.

Approval for this study was granted by the Office of Research Ethics at the University of Toronto on January 5, 2009, and by the Research Ethics Board at the hospital where the participants worked on January 19, 2009.

Data collection

The data in this study were gathered from one-on-one, face-to-face, in-depth interviews that each lasted between 30 and 70 minutes. (The interviews were conducted between
March and April of 2009.) According to Patton, “The task of the qualitative researcher is to provide a framework within which people can respond in a way that represents accurately and thoroughly their points of view...” [emphasis added] (p.21) (43). I attempted to provide such a framework by eliciting the participants’ responses to, as mentioned, semi-structured, open-ended questions about six hypothetical scenarios involving different forms of directed donations (Appendix C).

The purpose of using semi-structured, open-ended questions was to allow the participants to respond freely and in their own words, that is, without restricting their responses to a narrow set of predetermined response categories. The purpose of asking questions about hypothetical scenarios involving directed donations was to focus the participants’ attention on ethically relevant aspects of such donations (described below). The hypothetical scenarios were informed by the literature on directed donations and provided a basic theoretical structure to the interviews. The hypothetical scenarios were designed to guide the participants without leading them (46). As well, the hypothetical scenarios had an educative function: By illustrating real-life dimensions of directed donations, they enabled those participants who lacked knowledge about such donations to respond more thoughtfully and with a better understanding of their complexity.

Below are the six hypothetical scenarios that I presented to the participants. After each, I will briefly describe the distinguishing features given they were intended to present different ethical issues.
**Scenario 1:** A young man has died in a car accident on the way home from a skiing trip in northern Ontario. His father, who suffers from cardiovascular disease, has been on the waiting list for heart transplant surgery for two years. The young man’s family has agreed to donate their son’s organs, but has requested the heart be given to the father.

This scenario featured an example of a directed donation in which the donor has a genetic or familial relationship with the recipient.

**Scenario 2:** A middle-aged woman was struck by a car while jogging along a sidewalk in Toronto and suffered a fatal head injury. Her husband has a childhood friend who suffers from chronic liver failure and has been waiting for a liver transplant for over a year. The husband has agreed to donate his wife’s organs, but only if her liver is given to his childhood friend.

This scenario featured an example of a directed donation in which the donor’s family has a close emotional connection to the recipient. As well, the husband has made the donation of multiple organs *conditional* based upon his wife’s liver being given to his friend.

**Scenario 3:** A middle-aged woman with renal failure has been on Ontario’s waiting list for a kidney for over four years. A couple of days ago, she advertised her need in a local newspaper in the hope of finding a donor. Her children also distributed flyers and created a webpage called www.SaveMomsLife.com. A young man has just died in the hospital from a cerebral haemorrhage. His family, who had been touched by the woman’s emotional appeal in the newspaper, has stipulated that their son’s kidney be given to the woman.

This scenario featured an example of a directed donation in which the recipient is not known personally, but becomes identified to the donor’s family based on a public appeal for a donation.

**Scenario 4:** An elementary school teacher has been involved in a bicycle accident and dies at the hospital. Her husband has agreed to donate her organs, but requests that, as far as medically possible, the organs be given to children. He claims his wife had devoted her life to children, and so she had always wanted her organs to benefit children.

This scenario featured a directed donation in which the recipients were members of a designated group. It was included because donations to children appear to be more
acceptable to some authors in the literature than donations to most other recipient groups. Additionally, the deceased wife had a strong emotional attachment to children, and had even indicated her wish to donate her organs to children before she died.

**Scenario 5:** A middle-aged man has died from a cerebral haemorrhage. He carries an unusual donor card. It states, “Please give my organs, first, to members of LifeSharers, unless no suitable match can be found.” The card explains that LifeSharers is a donor organization whose members all agree to donate organs after death, but to give priority access to other members. LifeSharers can be contacted at a number on the card for information about other members in need.

This scenario featured another example of a directed donation in which the recipients are members of a designated group. This scenario was chosen because unlike most other group-based donations, with LifeSharers, the recipient group is not identified based on sociological characteristics. Additionally, LifeSharers appears to promote a noble goal: to encourage people to commit to posthumous organ donation.

**Scenario 6:** A teenaged man has suffered a fatal head injury during a hockey game at a Toronto arena. His parents are eager to donate their son’s organs so that he may “live on in others”, but stipulate that the organs be restricted from going to patients whose illness resulted from drug or alcohol abuse, or who are otherwise personally responsible for their illness. The parents explain that such patients do not deserve their son’s organs.

This scenario is another example of a directed donation in which the recipients are members of a designated group. It was included because, unlike the two group-based donations above, the donor’s parents in this scenario have not attempted to prioritize a specific group, but to systematically exclude a specific group from receiving organs. Further, the excluded recipients are those whom the parents believe had brought their illness upon themselves.
Interview process

At the beginning of the interview, I attempted to gain the participants' trust and make them feel at ease by letting them know that there were no right or wrong answers to the questions, that I appreciated that they had not researched the topic, that I did not have a special agenda other than to gain a sense of their general thoughts about directed donations, and that I would not be agreeing or disagreeing with their responses, or giving any normative indications. Because the participants were made to feel more comfortable, they were more inclined to speak honestly and openly. This, in turn, enhanced the overall credibility of the qualitative findings (43).

Next, I gave the participants a copy of the hypothetical scenarios, asked them to read the first scenario, and said: “Imagine that you are one of the people responsible for allocating organs in Ontario. Describe what you think should be done.” Then I asked the participants to read the second scenario, and said: “Again, you’re one of the people responsible for allocating organs in Ontario. What do you think should be done?” I repeated the same question for each of the scenarios. This question encouraged the participants to step into the imaginative scenario and play the role of a key decision-maker.

At different points throughout the interview I asked the participants to explain the differences in their responses between the different scenarios. I asked, for example: “How would you explain the differences in your responses between scenario one and scenario three?” This particular question sought a better understanding about the basis for the participants’ responses. Usually, the participants' responses were relatively
clear and thorough, but occasionally, I would seek greater clarity and detail by asking, for example: “How would you explain your last response?”, or, sometimes more specifically, “How would you explain your feeling that a personal relationship is a relevant consideration in deciding whether to accept a directed donation?”

Once I had a better indication of the participants’ general views about directed donations, I asked them to respond to a few alternative or opposing views from the literature. This was done to further stimulate the participants’ reflection on the issue. It also served as a check against any initial unreflective responses, and helped to further clarify the reasoning behind their views. As an example of such a tactic, if a participant appeared to be against directed donations that resulted from solicitation, I asked: “One of the views in the literature is that the donation might not have been available without the public appeal. How would you respond to such a view?”

Near the end of the interview, I asked the following two questions: “Are there any other circumstances under which you feel that a directed donation should be accepted?”, and, “Are there any other circumstances under which you feel that a directed donation should not be accepted?” These two questions were intended to give the participants a chance to speak about any directed donations, or related aspects, that were not featured in the scenarios, or that had not come up in conversation. Finally, I concluded the interview with the following general question, which allowed the participants to communicate any thoughts about the topic that they felt were important: “Is there anything that we haven’t talked about that you would like to share with me?”
After the interview finished, I encouraged the participants to e-mail or call me if they wanted to share any additional thoughts, which two of the participants did. During the analysis stage, I also contacted a couple of the participants by e-mail for clarification on their responses as well as to verify that my interpretation of their responses was accurate.19

Data analysis

The process by which I analyzed the participants’ responses, the data, included several interlinked stages – *immersion, deconstruction, classification, and representation* – each of which had its own sub-processes. In each of these stages I used selected analytic procedures from Strauss’s and Corbin’s grounded theory (45). The analysis began with *immersion*,20 through which I sought to become more familiar with the data through transcribing the interviews word-for-word, checking the transcripts for accuracy, and reading and re-reading the transcripts. I also wrote reflective memos, which contained

19 The hypothetical scenarios, and the questions I asked the participants about them, had undergone several minor revisions based on trial interviews that I conducted with 12 people, including friends, family members, colleagues in the health care industry, and my thesis supervisor. I had asked each interviewee for feedback on the strengths and weaknesses of my interview format. These interviewees also gave me tips on how I could make other interviewees feel more comfortable during the interview.

20 These general stages of data analysis – *immersion, deconstruction, classification, and representation* – were based on those outlined by Professor Nora Jacobson in her (2008) University of Toronto graduate course “Introduction to Qualitative Methods for Health Services & Policy Research”. I refer to them because they describe the process of data analysis, which is rather complex, in terms that are easier to understand. Further, they correspond closely with the analytic steps of grounded theory that are outlined by Strauss and Corbin (45). In the “Data analysis” section below, I explain why I chose not to complete one of the stages which Professor Jacobson called *linkage or organization*, and which occurs after *classification*. 
descriptive summaries of the interviews, my general first impressions, and preliminary interpretations of the data.

The next stage was *deconstruction*, the process through which I fragmented the data, breaking it down into various smaller pieces. In grounded theory, this process is called “open coding”, and one of its major analytic tasks is to assign labels, or codes, to the pieces of the data (45). The codes that I assigned were abstract representations of pieces of the data that I identified as being significant to the participant (45). During open coding, I assigned to each sentence or paragraph of each interview transcript one or more codes, for example, “types of benefit”, “donor benefit”, “family benefit”, “types of consent”, “first-person consent”, “presumed consent”, “types of relationships”, “familial relationship”, “emotional relationship”, “types of allocation” “equitable allocation”, and “discriminatory allocation”. As an illustration of how I went about open coding, consider the short excerpt below taken from an analyzed interview transcript. (The codes were abstracted from the data, and were not conceived prior to the analysis).

“They have a direct benefit [TYPES OF BENEFIT] [direct benefit], the donor family [family benefit], because they become a recipient family at the same time [immediate benefit]. There’s a direct give-receive benefit there [reciprocal benefit]. They lost their son but their husband lives. They lost their wife but their good friend lives.” [Analytic note: special benefit is possible if there is a special connection to the designated recipient]
Each of the codes that I abstracted from the data represented a concept. As such, the goal of open coding was to conceptualize the data (45) or, to put it differently, to lift the analysis off the ground.

In general, I went about open coding with two broad questions in mind: “What is going on in the data?”, and “What about directed donations is of importance to the participants?” The various reflective memos that I wrote during this stage included my thoughts and ideas about the relative importance of the identified concepts, how they illuminated aspects of the questions above, and which analytical gaps needed to be filled.

The next stage was classification, the process through which I reconstructed the pieces of data in order to form logical and meaningful analytic categories. A category is a broader abstract concept under which several related concepts can be subsumed. One of the purposes behind identifying concepts during open coding was to be able to group them under more abstract concepts, or categories (45). In grounded theory, when categories are identified, they are then further developed and linked to related subcategories (a category within a broader category). The analytic process is called “axial coding”, because the coding takes place around the axis of a category (45).

As an example of how I went about axial coding, I had noticed that the concepts, for example, “familial relationship”, “emotional relationship”, “friendship”, and “immediate connection”, could be categorized under the general concept of “relatedness”. I also noticed that the concepts, for example, “direct benefit”, “meaningful benefit”, “family
benefit”, “reciprocal benefit”, and “genuine benefit” could be conceptualized as “donor family benefit”. I further observed that these two distinct categories were closely connected. In the eyes of some participants, the donor’s family must be related to the designated recipient for them to benefit in a meaningful or special way from making the directed donation. It followed that “donor family benefit” was a subcategory of “relatedness”.

The reflective memos that I wrote during the classification stage contained my thoughts and ideas about the relationships among the different concepts, categories and subcategories. I also drew multiple diagrams to depict visually such relationships, which not only helped me to see more clearly how the concepts, categories and subcategories fit together, but also to spot holes in the overall analysis.

The final stage was representation, the process through which I shaped the results of the analysis for use by the intended audience: members of the transplant community. A primary goal in writing-up the results was to “tell the complicated story of [the] data in a way which convinces the reader of the merit and validity of [the] analysis” (p.93) (47). Accordingly, I presented various extracts of the participants’ responses as evidence of the categories, subcategories, and other interpretations. The overall representation of the results was both interpretive and descriptive.

In each of the stages above – immersion, deconstruction, classification, and representation – making comparisons was a critical sub-process. I constantly compared data with data, data with concepts, concepts with concepts, concepts with categories,
and categories with categories to identify similarities and differences. Further, although I presented the stages in sequential order, in practice, they were cyclical and often occurred simultaneously.

It is important to point out that I purposely did not complete one of the general stages of analysis called linkage or organization (which occurs after classification), which involves weaving the categories together into a theory. In grounded theory, the analytic step which corresponds with this stage is called “selective coding” (45). Its goal is to integrate major categories to form a larger theoretical scheme or theory – hence, the term grounded theory. The analysis centres on a select few (or even a single) higher level abstract categories that explain the phenomenon under study. However, according to Strauss and Corbin, theory development need not be the goal of using grounded theory procedures (45). They argue that the goal may be to organize the data around a set of well-developed analytic categories, and further that the procedures of grounded theory can and should be used flexibly depending on the reality and purpose of one’s research (45). Accordingly, I used grounded theory’s basic coding procedures to carry out an inductive analysis of the participants’ responses, or specifically to abstract from such responses several meaningful categories that represented what the participants felt was important about directed donations. Therefore, my study was not a “grounded theory” study.

If theory development is a researcher’s goal, then grounded theory’s theoretical roots in symbolic interactionism play a critical role in the overall analysis (at least in traditional versions of grounded theory) (45,48). The main focus of analysis is on trying to explain
the social processes involved in people’s construction of reality and meaning. Thus, if I had aimed to produce a grounded theory, my research question might have been, for example, “What are the basic social processes involved in transplant professionals’ moral reasoning about directed donations after death?” The intended result might have been a theory about the processes by which transplant professionals engage in moral reasoning as a function of social behaviour.

Credibility of data analysis

In qualitative research, “the researcher is the instrument” [emphasis added] (p.14) (43). This is because the analysis rests inevitably on the personal perspective, assumptions, and interpretations of the researcher. Critical self-awareness, then, or “reflexivity” as it is called in qualitative research, was an important part of ensuring that the analysis was credible. To be reflexive, I undertook an ongoing assessment of the assumptions that I brought to the research (e.g., about the ethics of directed donations, the transplant professionals whose views I studied, and the intended audience) and how they affected the data that I collected and my analysis of it. I also assessed during the coding processes whether I had prematurely foreclosed the discovery of concepts, whether I had forced the data into categories, and whether I had taken into account pieces of the data that contradicted or challenged my analysis.

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21 The reason why I have chosen to write this thesis in the first person is to emphasize the active role of the researcher in qualitative inquiry.

22 The types of questions that I asked as part of the process of reflexivity were based on those outlined in Patton’s “triangulated reflexive inquiry”, which involves reflexivity about one’s self, the people studied, and the intended audience (p.495) (43).
I engaged in peer-debriefing as an additional way to enhance the credibility of the analysis. Lincoln and Guba describe peer-debriefing as “a process of exposing oneself to a disinterested peer in a manner paralleling analytical sessions and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (p.308) (49). I met regularly with two peers to discuss my emerging ideas and insights about the data. Through their questioning and critiquing these peers helped to further expose my biases and assumptions. As well, the peer-debriefing forced me to justify my interpretations of the data, and thus allowed me to see if they seemed logical or plausible to disinterested observers.

The interpretations of the participants’ responses were my own. Another researcher might very likely have made different interpretations, because he or she would have brought to the data a different perspective and set of assumptions. What is important is that I attempted above to make the analytic processes through which I arrived at the interpretations as clear as possible. According to Strauss and Corbin, “once an analyst explains in detail how he or she arrived at a conceptualization, other researchers, regardless of their perspective, should be able to follow the analyst’s path of logic and agree that it is one plausible explanation for what is going on” (p.146) (45).23 I also tried above to articulate clearly the procedures that I used to collect the data, because the credibility of the one’s analytic findings depends, to a great extent, on the quality of the data gathered (43).

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23 To be sure, if a researcher had the same general perspective that I had, and followed the same basic procedures of data collection and data analysis, and carried out such procedures under a similar set of conditions, then it is possible that the researcher would produce similar analytic findings. To this extent, this study is “reproducible”, according to the definition stipulated by Strauss and Corbin (p. 266-267) (45). The point is that the credibility of the analytic findings is reinforced if they are able to be reproduced.
Further, by presenting the actual participants’ responses upon which I based the interpretations, others are able to judge for themselves whether they make sense (43). Indeed, what the participants actually said was the true substance of this study. The purpose of the analysis was simply to organize and explicate the data in a way that makes it easier to understand what the participants felt was important about directed donations. My own analysis was not meant to overshadow the participants’ views. Patton argues, “the skilled analyst is able to get out of the way of the data to let the data tell their own story” (p.457) (43).
CHAPTER 4 – RESULTS

In this chapter, I describe the results of my analysis of the interviews with the participants. The results are organized into various categories and subcategories depicting the participants’ views on different aspects of directed donations. I provide numerous quotes from participants to illustrate their views as well as to support my interpretations of them.

Category 1: Medical suitability

“In the end it comes down to science.”  

A main view among the participants was that the minimum prerequisite for permitting a directed donation was its fulfilment of the various medical requirements for a standard donation. The following participant’s response is representative of such a view: “So first and foremost is whether or not the heart would be appropriate for the father, meaning does the blood group and the body size match? Is this a medically appropriate fit? And if it's not medically feasible, that would eliminate any ethical dilemma.” As is partly evident in this response, and clearer in the response immediately below, to some of the participants, if the donation was not permissible from a medical standpoint, then whether the donation was acceptable from an ethical standpoint was no longer of significance: “…the medical issues are whether [the organ is] the right size or match, etcetera, because, you know, if it’s not an appropriate organ for that recipient then whether or not it’s right or wrong [to accept the directed donation] is a moot point.”

24 In this chapter, I included a special quote (highlighted in bold) from the participants to illustrate each of the categories and subcategories.

25 The views described in this chapter must be considered in light of the study’s limitations outlined in the “Discussion” chapter. Most important, the views do not necessarily represent the transplant professionals’ final thoughts on the topic of directed donations.
The participants cited several medical requirements for a directed donation. They placed most emphasis on the need for the designated recipient to be biologically compatible with the organ in terms of body size, body weight, blood type and tissue type. The health and viability of the donated organ was also stressed. As well, some participants considered it imperative that the designated recipient already be on the provincial waiting list for transplant surgery. It appeared that the reason was to guarantee that the recipient was suitable to receive an organ, as suggested in the following participant’s response: “*But the issue is, has the recipient been deemed within a [transplant] program to be an appropriate candidate? You know, because there’s many cases, well actually the recipient has cancer and so he’s not a candidate. So the first issue is, has the recipient cleared the process and is active on the list?*”

In one participant’s opinion, failing to ensure that the designated recipient was a medically suitable candidate would jeopardize his or her safety and well-being: “*When you’re talking about the organ not being the best match, why would the transplant team want to put the recipient at harm? That doesn’t make any sense. It completely goes against medical standards. So the organ stops working, then what?*” In another participant’s view, if the designated recipient was not medically suitable, then the donated organ would fail to yield its maximum medical benefit: “*The reason I think it’s difficult to allow those sorts of [donations] is that the people who are donating don’t necessarily know how their organs can best be used. So there may not be a child that could benefit greatly from any of those organs: They’re not an appropriate blood type, size, whatever, to benefit. So we wouldn’t be making the best use of those organs. You know, they don’t often know that.*”
Category 2: Informing the family’s decision

“Again, the family has the right to know.”

The majority of the participants believed that, upon any request from a family to direct an organ, the transplant team should carefully explain to the family the various practical and ethical aspects of organ donation and transplantation. As the following quote illustrates, the participants appeared to believe that imparting such information should be an initial response: “With any of these requests, I’d want to have a discussion with the family. I think that’s the standard first step with any request. You know, sit them down and explain to them and really get across to them what they’re asking us to do…and how that would fit into the allocation system that we’ve established.”

The participants believed that the family should be informed that the designated recipient must be biologically compatible with the organ (and that failing to guarantee a suitable match could result in serious physical harm to the recipient); about the medical and ethical criteria upon which the provincial organ allocation system determines recipients’ priority for organs; about the information that is recorded about recipient candidates (e.g., blood and tissue type, body size, level of need); about the information that is not recorded (e.g., religious affiliation, ethnicity, club membership); and about the likely possibility that there are other recipients on the waiting list who have waited longer for a transplant or who are in worse physical condition than the designated recipient.

Several of the participants believed that one of the purposes of imparting such information was to allow the family to make an “informed decision” or to give “informed consent” to donate. The moral weight that these participants implicitly or explicitly
attached to enabling families to make informed decisions is demonstrated in this quote:

“But again, it goes back to informed consent on the side of the donor family. So if they have seen someone in the media and want to direct an organ to them and they’re not at the top of list, then they have the right to know that. And they have the right to know what our [allocation] process is, and they have the right to know that in these circumstances we generally don’t deviate.” It is apparent in this response that the participant viewed enabling the family to provide informed consent as morally obligatory.

To increase a family’s understanding of their decision, a few of the participants conveyed the impression that it would sometimes be necessary to engage the family in moral reasoning. In the following quote, the participant showed how the notion of reciprocal responsibilities could be demonstrated to a family: “You would have to educate [the family] a little bit…ask them would you accept an organ from someone of any ethnicity? Okay, well then why can’t you give to someone of any ethnicity? Would you accept an organ from someone of any colour? Well then why can’t you give to someone of any colour? So there’s no real basis behind [the family’s request] that’s reasonable, and you try to show them that.”

A similar attempt to encourage the family to contemplate the morality of their wish to direct an organ is illustrated in the participant’s response immediately below. In it, the participant described what could be said to the father who, in the hypothetical scenario, restricted his deceased son’s organs from going to recipients who were “personally responsible” for their illness (scenario six): “I would put some arguments out there for him to think about…Have you eaten McDonalds? Then we can’t treat you for
cardiovascular disease, right, because you’ve eaten too much fat, and you should’ve
known better. Diabetes. I’m sorry you drank too much Kool-Aid when you were a kid.
You drank pop as an adult…Doughnuts?...I wouldn’t say it quite like that, it’s a sensitive
time, but I would help him to see there is no where to draw the line.”

Some of the participants expressed the opinion that, in most cases, a family’s request to
direct an organ may be a spontaneous or irrational response to their relative’s death, as
indicated in the following quote: “…you know, these families are in shock. They’re
grieving. Sometimes they say the first thing that comes out of their mouth, however
unreasonable it may be.” A few of the participants further suggested that such requests
are likely based on misinformation or misconceptions. This is partly illustrated in the
following participant’s response: “People don’t necessarily appreciate what goes on.
They may think it’s as simple as taking [the organ] out and putting it in. They don’t really
understand the complexity of what actually happens...So a lot of it comes down to
informing them of the reality of the situation, from media to things you see on TV.
Sometimes people have an unrealistic view of what goes on in organ donation.”

**Subcategory: Changing the family’s mind**

“You can gently persuade them, but that’s all you can do.”

Some of the participants conveyed the impression that the goal of increasing the
family’s understanding about the practical and ethical aspects of organ donation is to
“gently persuade” them to donate instead to the general pool of recipients. This is
evident in the following participant’s response: “It’s the same thing from the very start.
Sit down with the family, explain to them how the allocation system is done, and how it’s
done to be safe, fair and equitable. Make sure that they understand there are other people who have been waiting just as long or longer, who are in just as great a need and just as deserving…and hope that they would change their mind and allocate it according to the usual system.”

The supposition that a family would likely agree to donate in a non-directed manner after reflecting on the relevant considerations appeared to be based on firsthand experience for a couple of the participants. In the following quote, one of the participants described such an experience: “I have been in situations where, for example, we will only give the liver to someone who has not been a drinker, or I do not want this kidney to go to a person who is [of a certain ethnicity]…and with proper explanation and understanding in the family, I think in some cases, and I remember in both those cases, yes, we got around that situation, and the family ultimately still felt comfortable donating the organs even though they had put this caveat on it…So I think some of these cases, that’s the initial scenario you’re dealt with, but I think some of them you can overcome if the person doing the asking [for organ donation] properly explains and educates the family.” Another participant described a similar experience: “Religious affiliation…that’s one that I’ve seen before in talking to families. They’ve asked can this go to a Catholic, those types of things…When you explain the allocation and that we don’t capture that information, it’s not part of the medical decision-making, so we can’t honour those types of requests. I’ve never had anybody that’s said then we don’t want to donate.”
Category 3: Relatedness

“...but if there’s a strong connection, that’s a pretty special thing.”

Most of the participants believed that a family should be allowed to direct an organ of a deceased relative to a family member in need. They emphasized the “biological ties”, “emotional depth and closeness”, “immediate connections”, or “personal attachments” that exist between relatives as the justification for permitting directed donations to family members.

As shown in the following quote, one of the participants believed that the desire to direct an organ to a relative sprung naturally out of a selfless concern for his or her well-being: “I think there’s that, you know, a parent would do anything for a child to help them get better. And I also think that an adult child would do anything for a parent who’s under those situations. In a family situation you would do whatever you could to help that person get better.” Further, referring to the hypothetical scenario in which the family requested that the son’s heart be given to the father (scenario one), one of the participants stated, “…it would be inhuman to not allow a son to give to his father.” This response underscored the participant’s view that refusing to honour the family’s request would seem morally unacceptable.

More than half of the participants also believed that a donor, or the donor’s family, should be allowed to direct an organ to a recipient who they knew personally, but who was not necessarily a relative, for example, a friend. The close emotional connection to such recipients was believed to warrant the donation. Referring to the hypothetical scenario in which the husband designated a childhood friend to receive his deceased
wife’s liver (scenario two), one of the participants responded, “…you know, emotional relationships, as opposed to just biological relationships, have also been given precedence, so in this scenario with wanting to help someone you know, it’s still a reasonable request. It’s not beyond the norm that you would want to help someone you know personally versus a stranger on the list…again, those emotional ties have bearing on it.”

**Subcategory: Donor family benefit**

“…they get something special and meaningful out this.”

A few of the participants thought that the kind of benefit a family received through donating to someone who they knew personally is uniquely genuine and emotional. As such, they considered it important that a family be given the opportunity to realize such a benefit. One of the participants appeared to believe that without an immediate connection there would be no opportunity for the family to accrue the type of benefit needed to justify the directed donation, as partly illustrated in the following response:

“They have a direct benefit, the donor family, because they become a recipient family at the same time. There’s a direct give-receive benefit there. They lost their son but their husband lives. They lost their wife but their good friend lives. Lost my son and some strange lady whose picture I saw lives, that’s not equivalent in my mind.”

Allowing a family to direct an organ to a recipient with whom they had a close emotional connection was also viewed as a way to enhance the meaning of a relative’s death for the family. This view is best illustrated in the following participant’s response: “I think that when you can direct a loved one’s organs to someone who you know personally
who is in need, I think that’s a very powerful way of finding meaning, and having closer relationships with people as you go through life…I think that it can be very helpful not only for the patient who’s going to get a heart but also for the family’s healing, and that the son can live on in the father…there is meaning, tangible, very visible meaning.” A couple of the participants further believed that accepting the family’s request would help ease the emotional impact of the relative’s death. This is evident in the following quote: “As important as recipients are, we also have to remember that these are very tragic times for these donor families, and we need to help them through the process. If there are specific emotional things that we can do to support them, I think that also has to come into our thinking.”

**Subcategory: Non-relatedness**

“There’s no direct relationship, so what does it offer the [donor’s] family?”

Several of the participants thought that it was unjustifiable to accept a directed donation if there was no close or pre-existing emotional relationship between the donor, or the donor’s family, and the designated recipient. Referring to the hypothetical scenario in which the donor’s family designated a woman who was identified through a public appeal for a donation (scenario three), one of the participants stated: “It doesn’t resemble scenario one or two in that it’s not a long-standing, pre-existing relationship. It is a relationship that comes up in the context, that’s arisen by accident. It’s arisen because of the need. It’s grown out of sort of an appeal…by the accidental presence of [an appeal].” To this participant, the lack of a close or pre-existing emotional relationship precluded the family’s “opportunity to…receive the same kind of meaningful benefit” that justified accepting a directed donation. Reflecting on the same scenario, one of the
participants commented on the difference between donating to related versus unrelated recipients: “So I would have more difficulty with this [scenario] because there’s no direct relationship. When it’s a direct relationship, and so the transplant is going to benefit someone you care for and who you know, but a random person who is on a website has no more bearing on your life than someone whose picture you don’t see.”

The same participant considered a family’s desire to save an unrelated recipient to be insincere, but that “saving their husband, or saving their friend, that’s real, because they lived it. They watched their friend get sick…it’s a longer process.”

Category 4: Public appeals for organs

“So in terms of social justice I don’t think it’s fair that they have an advantage.”

Most of the participants were against permitting an organ to be directed to a recipient who became identified to the donor or the donor’s family through a public appeal for an organ. (I have already mentioned that many of the participants believed that a personal connection to the designated recipient was a necessary condition for accepting a directed donation.) It was generally viewed that solicited donations gave recipients who are better equipped to transmit their need an unfair advantage to obtain an organ. As evidence of such a view, consider the following participant’s response to the hypothetical scenario in which the mother issued a public plea for an organ (scenario three): “But then this woman gets her transplant because she’s the squeaky wheel...So the family has the money to do the advertising, but the poor person who has been on

26 It is important to note that a couple of the participants believed that the type of relationship between the donor, or the donor’s family, and the designated recipient was not a relevant consideration in deciding whether to accept a directed donation.
the waiting list for eight years, which is feasible, we know they wait that long, who doesn’t have two cents to rub together can’t make the appeal and therefore is denied this kidney, which may have been their match, because they don’t have the funds to do it.” Consider also the response from another participant to the same scenario: “I don’t think this is just, because there are a lot of people who don’t have the resources to advertise who need this just as badly as this person. So in terms of social justice I don’t think it’s fair that they have an advantage. There are a million stories that I think if this family knew about them, how could they decide?”

A couple of the participants drew parallels between soliciting donations and buying organs (which is illegal in Canada), apparently because both depend on material means to obtain the organs. Similarly, one of the participants believed that solicited donations smacked of “two-tier health care”, which the participant considered unjust, as partly suggested in the following response: “Should that person with money get surgery first, get access to health care? It should be universal and it should be justly given to everyone.”

A few of the participants were concerned that public appeals tended to contain inaccurate or deceptive information to strengthen their emotional appeal. One of the participants stated, “People will do whatever they want to get a donor…and that is seen everyday. They might lie to the media, lie to the public…Truth doesn’t always make for good publicity.” Similarly, another participant remarked that “emotional pleas” are “very one-sided” in that they call attention only to the need of the particular identified recipient. In this participant’s view, “…there’s probably not many recipients who couldn’t make an
emotional case for why they’re the most urgent person on the waiting list. Nobody enjoys being on dialysis three times a week, for four hours at a time.”

Another concern that the participants raised was that solicited donations might occur so frequently as to largely undermine the fairness of the waiting list. The following participant’s response captures this concern: “So in the first two [scenarios] we saw families, close friends, a need based on that...[which] are only going to happen once in a blue moon. This other, it’s like it’s going to change the system radically across the board...We could have everybody advertising and everybody directing things, and then only the people who didn’t have the wherewithal to advertise wouldn’t be getting organs...and everybody is going to be advertising, and how do we maintain some kind of equity on the list?”

Subcategory: Raising awareness and generating donations

“...it’s an extra organ that would not have been available otherwise.”

In contrast to the participants’ general opposition to solicited donations, a few of the participants were in favour of solicited donations, because they felt that such donations raised public awareness about organ donation and stimulated donations. As evidence of this view, consider the following response from one of the participants: “These people would not have come forward if they were not emotionally touched at some level [by the public appeal]...And yes I know it means this person gets to be transplanted sooner, but the benefit is it’s an extra person in the chain. So that they have used their own resources to do this, presumably that will take them off the list faster, and move other
Implicit in this response is the participant’s view that the interests of patients in receiving transplants, or advancing on the waiting list, generally override concerns about some recipients bypassing other recipients. Consider also the following response from a different participant, as evidence of the belief that solicitation increases awareness about organ donation: “One could argue that these media appeals educate people about the benefits of donation…We are in the midst of a media event right now and my experience has been, although the individual benefits, I believe there is generally a societal benefit…So on balance I so far see more good than harm come from it.”

**Category 5: Group-based donations**

“It just gives people too much power to discriminate, and mass discrimination like that should not be tolerated.”

Most of the participants were strongly against allowing a donor, or the donor’s family, to designate a member of a particular identifiable group of recipients. They considered it unfair to make distinctions in the treatment of different categories of patients, especially on grounds of ethnicity, gender, religious faith, sexual orientation, cause of illness, or other characteristics considered discriminatory or prejudicial. One of the participants

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27 By contrast, one participant believed it was impossible to determine whether a donation would not have occurred without the public appeal.

28 An explanation about the composition of this particular category is needed. I elicited the participants’ responses to three hypothetical scenarios that involved different group-based donations (scenarios four, five and six). Despite having discovered patterns and similarities across the responses to the three scenarios, I have decided to organize their views under subcategories that reflect the type of group-based donation: “Donations to children”, “Donations to members of LifeSharers” and “Donations based on recipients’ cause of illness”. Doing so makes the participants’ responses clearer. I am making my decision clear in case it was assumed that I had let the scenarios predetermine what participants believed was significant about group-based donations.
opined, “Once you start allowing any categorization beyond medical, then you open the door to discriminatory practices in terms of allocating organs.” Another participant stated, “The bottom line is that there has to be no racial, ethnic, um, sexual orientation, or any discrimination on any of these grounds...In my mind, no chance of it...Would not support it.” Another participant stated, “You’re going to be asking the state or surrogate of the state to discriminate and that gets pretty messy.”

A couple of the participants expressed their opposition to group-based donations in distinctly ethical terms, as illustrated in the following quote: “You can’t start specifying groups and attaching moral priority depending on the diagnosis and age. Then I think you’re into unethical grounds. Everyone is different in what they’re going to value, and think that person or group should get organs first...You know, they deserve based on medical reasons. When you start looking at who should get it based on social reasons...it’s morally and ethically wrong I think.” As another example, consider the following participant’s response: “I would say that the general ethical principles about how we expect to treat people and be treated ourselves, and conditions that we would agree generally are qualities about people that would be unacceptable to change the way we deal with them, that those same concerns should be respected if you’re talking about organ donation.”

Many of the participants were concerned that group-based donations would undermine the integrity of the transplant system, as partly demonstrated in the following response: “Donations with those discriminatory conditions...that’s something as a [transplant]
program that we cannot tolerate. It’s a situation that is not healthy for the program and not healthy for society in general.”

Some of the participants further regarded group-based donations as problematic from a practical standpoint, because of the difficulty in identifying recipients based on non-medical criteria. As one of the participants stated, “We’d have to explain to the family that…we don’t list people by whether they’re members of a specific group. We don’t list on the basis of religious groups. We don’t do specific groups like that. It would be impossible for us to actually facilitate a request like that.” Another participant thought that the amount of “time and effort that would be needed to go through and micromanage all of these requests” would be unreasonable.

**Subcategory: Slippery slope and opening the floodgates**

“So when you look at these things, if you start it, where does it stop?”

Certain of the participants believed that, if a precedent were set allowing organs to be directed to designated groups of recipients, then organ donation would approach a “slippery slope” which ended in having to accept increasingly more inappropriate forms of group-based donations. “Opening the floodgates” was another metaphor invoked to describe the flow of group-based donations that several of the participants worried would occur once the regulation preventing such donations was removed.29 As an example of these concerns, consider the following participant’s response: “If we do allow him to make this directed donation, is that just going to start the slippery slope of...”

29 Most references to the slippery slope and floodgates metaphors were made specifically in connection to group-based donations. However, a couple participants believed that the danger of a slippery slope would occur if any donation to a non-family member was accepted.
me, you, and everyone else saying you can have my organs if it goes to certain people? So then you would have an entire group of society who will never receive organ transplantation because they are poor, because of their skin, because they’re not the right religion….If we allow this to happen, is that what the future is going to be? The floodgates.” The following quote is another example of such concerns: “..well, actually, then a person may want to donate to an older person, or say I don’t want to donate to a woman, or to a man, or…so I think we have to be careful about that and not let the floodgates open. That’s my view.”

**Subcategory: Donations to children**

“Children are probably the least offensive group…but does a child deserve it any more than an adult?”

Most of the participants were implicitly or explicitly against allowing directed donations to children. A couple of the participants expressed the view that children should not qualify for special treatment, as suggested in the following quote: “*But there are other perfectly well and deserving people on the list who aren’t children, who need those organs.*” Another participant believed that prioritizing children would be unfair because on average children waited considerably less time for an organ compared to adults.

By contrast, a small minority of the participants believed that it was acceptable to designate children. They thought that allowing such donations would be consistent with the priority that is already given children in the routine allocation of some organs, as illustrated in the following quote: “*Trillium Gift of Life already discriminates between children and adults and gives priority to children so [allowing donations to children]*
would be consistent with that.” Further, a few participants believed that allowing donations to children was justifiable because children tend to suffer more than adults do as a result of a prolonged need for transplantation, as the following quote demonstrates: “I think, it’s that children have a much poorer quality of life and a much greater long term impact on their lives not receiving a kidney and benefit proportionally greater I think. So I don’t have any problem with that.”

**Subcategory: Donations to members of LifeSharers**

“It’s this whole membership idea that I’m against, these cliques and clubs, and if you’re a member then you have privileges.”

All of the participants were against permitting donations to members of LifeSharers. They considered it unfair, or even discriminatory, to prioritize members of a self-established donor group. One of the participants asserted that joining LifeSharers simply to increase one’s chance to receive an organ was similar to “buying an insurance policy”, and further that the organization “sets up a two-tier system, which is not ideal.” Another problem with LifeSharers, which several of the participants raised, was that the option to become a member could not be universally offered, as illustrated in the following quote: “People who haven’t heard about [LifeSharers] for many reasons are disadvantaged...there’s going to be people who don’t know about it, or understand it. And do they all get the same information about the benefits of membership? To me it runs the risk of leaving people out. Those in the know get and those not in the know don’t get. So it creates a bigger inequity.” As well, several of the participants questioned whether LifeSharers even had the legal authority to influence organ donation practices: “But [LifeSharers is] making health policy and they’re not in a position to make health
policy. That would be like you and I making some decision, you know, let’s just go out and do this…make a website…like we have no legislative background…[LifeSharers] holds no strength.”

Despite the general disapproval of LifeSharers, a few of the participants expressed support for the notion of reciprocal responsibilities in organ donation, which they believed the organization promoted, as the following quote demonstrates: “At a personal level [LifeSharers] resonates with me because I certainly believe that rights have to be balanced with responsibilities, and that having some sense of being responsible and making it clear that you recognize your responsibilities to the greater good, or reinforcing those behaviours is generally a good thing.”

**Subcategory: Donations based on recipients’ cause of illness**

“So it’s very difficult to define personal responsibility for illness.”

All of the participants were opposed to allowing a family to restrict organs from going to recipients who they deemed personally responsible for their own sickness, for example, drug or alcohol users. They did not think that it was possible to measure, accurately, personal responsibility, as the following quote illustrates: “It’s almost, well from a purely practical point of view, it’s almost impossible to say for sure that anybody who has lost an organ is because of personal responsibility. One could argue that anyone whose had diabetes and didn’t control their diabetes very well or had hypertension and didn’t take their pills properly or whatever are personally responsible. So I think that you have to say to [the family], we don’t have any mechanism of determining that.” Another participant offered a similar view: “It seems intuitive but it’s difficult to define the idea of
who’s responsible for their illness…What about somebody who has been overweight for 30 or 40 years and has coronary artery disease and had a couple heart attacks and now needs a transplant, are they responsible for their disease? That becomes harder to define. Or, there’s an interplay between genetics, and nature, nurture, all kinds of things like that. So it’s very hard to define personal responsibility for illness. There are genetic issues that modify susceptibility to disease based on these things.”

A main view among the participants was that a person’s misguided actions or behaviour should not exclude him or her from equal consideration for transplantation, as illustrated in the following quote: “Everybody makes mistakes in their lives. And if you end up needing a transplant it should not be held against you.”

Several of the participants emphasized the need to inform donors’ families that patients with active drug or alcohol addictions are automatically excluded from consideration for transplant surgery, and that all recipients meet various criteria to ensure that organs are used effectively: “I guess I would explain to the family that when such individuals are put on the list, they’ve gone through an extensive psychiatric process to ensure that they understand what they’ve done, and that they are appropriately treated, and in that category, with the counselling post transplant the recidivism rates are low enough that the transplant community believes that they are acceptable transplant candidates, otherwise we couldn’t offer them transplants.”
Category 6: Medical urgency

“...it’s reasonable only if there’s nobody who appears to be in urgent need of a transplant that day or that week.”

An important concern among the participants was that a patient in urgent need of an organ might be seriously harmed, or die, if an organ that would normally have been given to him or her was instead given to a recipient of the family’s choice, whose need was less critical. As an illustration of such a concern, consider the following participant’s response: “If the father is lower on the list he’s probably not as sick as people higher up on the list. And the people who we have listed as status three and four are typically very ill and getting this heart may actually save their lives, and the father would have time to wait. He has the ability to get sicker before he has his transplant. So I think if he were low on the list my first concern is someone’s going to die if the father’s given the heart.”

Accordingly, many of the participants thought that a recipient’s urgent need of an organ should automatically trump a family’s wish to designate the recipient – even if the designated recipient is a family member. The following participant’s response illustrates this belief: “I’m going to backtrack a second here and say that if someone was high status on the list, I would follow our traditional mechanism [of allocating organs]. I would have to do that. So if there was somebody who was higher status and by that I mean much more likely to die, I think the system we have put in place is such that I would allocate that heart. If the father was the same status as the other individual, then I myself would be comfortable with the heart going to the father.”

The few participants who were completely against directed donations believed that all organs should be distributed based on medical need, as the following quote
demonstrates: “There has to be equal access to this resource. So the bottom line for me in these scenarios is the person who needs the organs the most should get it.”

**Category 7: Conditional donations**

“So I guess you bite the bullet and accept the condition because…the good outweighs the bad I think.”

Some of the participants believed that, under certain circumstances, a family’s wish to direct an organ – that would normally be rejected as unethical – should be accepted, if the family would otherwise withdraw the donation. One participant stated, “I think at that point you have to weigh the benefit versus the loss, and obviously the loss of potentially eight organs is huge…so I still would think [the family] is not right, but it should happen. The saving of life should take precedence in these types of situations.” Another participant held a similar view: “How equitable is it to deny other people on the list? If you say no to directing a kidney donation and from that you end up loosing a heart, lung, a liver, and another kidney donation, I think there’s a greater inequity in that than deviating in one particular case.” As revealed in these quotes, and even more clearly so in the following quote, it was thought that the interests of recipients in receiving transplants should be given precedence with some types of conditional donations: “I would still value saving the life of the recipient above turning the organs down. I would prioritize that principle of saving a life higher than sort of the general concern about fairness.”
To be sure, a few of the participants believed that a conditional donation should not be accepted if it was considered discriminatory or prejudicial, even if accepting it would result in the obtainment of several organs.

Subcategory: Manipulation

“I just don’t like the manipulative factor, it bothers me.”

There were also several participants who appeared to believe that a condition placed upon a donation did not make accepting it more compelling. They did not believe that the transplant team should ever submit to such a demand, and further referred to conditional donations as “blackmail”, “manipulative” and “coercive”. Consider the following participant’s response: “Ok so the condition is if you let me direct this liver only to this person, the friend, then you can harvest other organs. Absolutely not. I don’t feel that’s right at all. That’s manipulation, coercion. Absolutely not.” Another participant expressed a similar belief: “I don’t think we can be blackmailed as to where the organs go. At the end of the day, maybe they will say, well, we’re not going to donate, and the organs get wasted.”

Category 8: Lack of anonymity and its potential harms

“Are you setting those two up for future problems, since they know each other?”

Some of the participants expressed the concern that, with donations to particular designated recipients, the lack of mutual anonymity between the recipient and donor, and by extension, their families, exposed both parties to emotional, psychological, and other risks. Consider the following quote: "There’s potential for horrible scenarios with
directed donations...Let’s say [the donor’s family] approaches the [recipient’s family] and they find out they’re not people who they’re comfortable with. Oh my god my son’s got that person’s organ in them. And we hear in the news where people have donated and...they want their organ back, or they want compensation for it. All that psychological trauma, you know, we don’t want to harm our donors or recipients in this process, and I think we would be.”

One of the participants believed that directed donations to family members were unacceptable because of the increased "burden of survival" on the recipient. Another participant stated, “So there is a danger I think that there is going to be too much emotion invested in the organ of a loved one”, which the participant believed might cause the recipient to experience “guilt or kind of grief…if the [organ] didn’t work particularly well.”

Accordingly, several of the participants believed that it was important that the recipient be informed about the risks associated with knowing or being known by the donor or the donor’s family. Consider the following participant’s response to the hypothetical scenario in which the husband expressed a wish to direct his wife’s liver to his childhood friend (scenario two): “It’s also about asking the recipient how they feel about it…So how would this woman feel about having her friend’s wife’s liver? What would the psychological impact be on her as well? Because we always have to look at the well-being and mental health of the recipient…and would she be able to tolerate that? Would she feel obligated to the husband in some way? You know, would she feel that she always had to pay tribute to her friend?”
In one participant’s opinion, if the recipient and donor’s family know each other, “boundaries” would have to be established and “agreed on in advance” of the donation, reflecting the participant’s belief that with such donations “good fences make for good neighbours.”

Category 9: Preserving public trust

“…if we start to allow these things, then indeed people may lose trust in the system.”

A major concern among some of the participants was that allowing directed donations might undermine the trust that patients and the public have in the transplant community to distribute organs fairly, as the following participant’s response demonstrates: “And so I think again it comes back to the trust our patients place in us to do this fairly and equitably, and if we start jiggling around with that, then you weaken that trust…” The participants believed that a loss of trust might, in turn, decrease people’s willingness to donate, as illustrated in the following quote: “…the negative backlash that would happen if not just with the patients on the list who have trusted their lives with us but the greater public realized that people were being chosen and picked based on non-medical factors…You could really do a disservice to organ donation…and it would potentially affect your organ donation rates.” As a further illustration, consider another quote: “…if directed donation from deceased donors were allowed to become commonplace, it would probably decrease donation rates because people would become cynical about the process. You would have the perception that it’s not equal access to care…Once you open the door to manipulation then it raises doubt in the public’s mind about the integrity of the allocation system so then people become unwilling to donate.”
Category 10: Need for a policy

“I think the [Trillium] Gift of Life...ought to be setting a policy because they represent society.”

Many of the participants believed that Ontario’s organ donation agency should establish a policy to govern directed donations. In several of the participants’ opinion, such a policy should not specify “everything in black and white”, but rather, be “open” and “flexible” enough to accommodate the multiple different variables that each new case of directed donation will present. One participant responded, “…because every donation is going to be unique, um, there may be a precedent, but every precedent is going to be different with each individual case.” Another participant offered a similar response: “There’s going to be different circumstances, so although I think you need to have a policy, you know, you can’t have one policy that says no to directed donation versus yes we can accept any directed donation. I think these should be handled case-by-case.” Despite these participants’ preference for a flexible policy, they generally shared the belief that such a policy should deny categorically any directed donations that are considered discriminatory or prejudicial.

In contrast to the views above, a few of the participants expressed a preference for a more rigid policy, one which limited the need for ad hoc judgements: “But I think it is better just to have rules because otherwise you’re putting unreasonable pressure on people to make a decision, and I think may be getting away from what is logical and rational to what will be emotional decisions which, you know, it’s just a lot harder.” In another participant’s view, directed donations left “too much room for abuse, or drawing fine lines, and interpretation” and therefore the participant favoured a policy which prohibited all directed donations. Several of the participants further emphasized the
importance of making any policy established to govern directed donations transparent and understandable to the public.
CHAPTER 5 – DISCUSSION

In this chapter, I describe the ways in which the views of the transplant professionals in this study were similar to and different from the views of the authors in the literature on directed donations from deceased donors. I also explain the implications of this study’s results for transplant practice, identify the limitations of this study, and suggest possible future research on directed donations.

How do the results compare with the literature?

There were some important similarities, but also differences between the views of the participants in this study and the views of authors in the literature about the acceptability of directed donations after death.

A key difference was the considerable weight that the participants placed on making sure that a directed donation was acceptable from a medical standpoint. This consideration was given only scant attention in the literature (19). Perhaps most authors simply took for granted, for example, that an organ would need to be compatible with the designated recipient; however, this consideration seems too important in assessing the acceptability of directed donations to remain implicit. Recall that one of the participants was concerned that failing to ensure a suitable match could seriously harm the recipient, because a poor match would increase the chance that the recipient’s body would reject the organ. Similarly, another participant believed that a suitable match was needed to ensure the best medical use of the organ. Maximizing an organ’s usefulness conforms with the principle of medical utility, the goal of which is to secure the greatest
benefit from the transplant operation. As mentioned, medical utility is a principal ethical criterion upon which organs are distributed in Ontario.

Pennings was one of only a few authors who addressed the issue of medical suitability (19). He stated that, if a recipient who receives a directed organ is a worse match than the top ranked recipient – who, by definition, is a near perfect match – then the transplantation as well as the organ is more likely to fail. As a result, Pennings argued that “the utility of the directed organ is lower than when the organ had been allocated on the basis of the [standard] medical criteria” (p.42). A question worth exploring, then, is how well-matched a directed organ must be to warrant accepting it. Is it morally acceptable, for example, to transplant an organ into a designated recipient if it would survive only half as long as it would in the recipient at the top of the waiting list?

Another important difference was the significant emphasis that the participants placed on ensuring that a family’s decision to direct an organ was based on knowledge of the relevant practical and ethical considerations. This notion of enabling a family to give informed consent to donate was given very little attention in the literature (20). Recall that the participants believed that, in response to a family’s wish to direct an organ, they should be educated about how organs are normally allocated and the ethical justification for doing so. This included explaining that there are likely other recipients who have waited longer for an organ or who are in greater need compared to the designated recipient. Such information would allow the family to evaluate the moral basis of their decision from a more informed perspective. Some of the participants
believed, as mentioned above, that imparting such information might even convince the family to donate in accordance with the standard criteria.

The International Transplant Nurses Society and The Transplantation Society appear to be the only authors who mentioned, at least implicitly, the need to inform families (20). Reflecting on one of the real-life cases presented in the *Transplantation’s* forum on directed donations, described above, the International Transplant Nurses Society concluded that the family’s wish to direct an organ may have resulted from the transplant team’s failure to adequately educate the family about organ donation. Further, reflecting on a different case presented by the forum, The Transplantation Society argued that the donor might not have attached a condition to the donation based upon the race of the recipient if “he had understood the consequences of his demand” (p.1532) (20).

Another key difference was the importance the participants attached to ensuring that a recipient in urgent need of an organ is given priority over a designated recipient whose need is less critical. The participants generally considered a patient’s need urgent if he or she faced imminent death without a transplant. Such concern for the interests of patients in urgent need was nearly absent in the literature. By contrast, in the views of many participants, an ethical condition for accepting a directed donation was that the donation would not, in effect, deprive a highly urgent recipient of an organ. Recall that many of the participants believed that even a family’s wish to designate a close relative should not supersede the interests of a patient in urgent need.
The International Transplant Nurses Society appeared to be the only authors who expressed concern specifically for recipients in critical need (20). Although they did not explicitly argue that highly urgent recipients should always be given precedence, it was perhaps implied in their assertion that “Directed donation to named individuals should be acceptable, although it can disadvantage a small proportion of transplant recipients, for example, Super Urgent Liver Patients” (p.1534).

Another important difference was the participants’ concern that, with donations to a particular designated recipient (not a group), it would be impossible to make sure that the recipient and the donor, and by extension, their families, remain mutually anonymous. As previously mentioned, in Ontario, the law requires that the identities of the donor and the recipient are concealed to protect both parties’ privacy.30 Recall that the participants believed that disclosure of the patients’ identities exposed their families to emotional, psychological, or other risks. These risks ranged from being disappointed with the donor’s family upon meeting them for the first time after the transplant, to possible future demands from either the donor’s or the recipient’s family, for example, a demand for compensation.

As well, as discussed above, some of the participants were concerned about the potential harms that a recipient might endure as a result of receiving an organ specifically from a relative or close friend. It was believed, for example, that the emotional attachment to the organ might place considerable pressure on the recipient (pressure from others and on oneself) to ensure the organ’s survival, or to show enough

30 Interestingly, it appears that the law in Ontario would prohibit all directed donations to individual designated recipients, which highlights a tension between law and morality.
gratitude to the donor’s family. Given the possibility of such perceived obligations or expectations, it is understandable that several of the participants believed that the transplant team should obtain a recipient’s consent to receive a directed donation after informing him or her about the related “psychosocial risks”. A discussion of the risks associated with the lack of mutual anonymity between the donor and recipient and their families appeared to be lacking in the literature.

A key similarity among the views of the participants and those of the authors was their shared belief that a donor, or the donor’s family, should be allowed to direct an organ to a recipient known to them personally. Similar to various authors (11,16,17,19-25), the participants considered a familial or close emotional connection to the designated recipient justification for allowing this category of directed donations. Recall, however, that part of the grounds for granting such freedom, in the views of a few participants, was to make the death of a relative more “meaningful” for the donor’s family, as well as to ease the emotional impact of the death. These particular benefits seemed to be overlooked in the literature.

Another similarity was that, like various authors (11,16-18), many of the participants did not believe that a donor or the donor’s family should be permitted to designate a recipient who is not known personally. Such absence of a close or pre-existing emotional connection to the designated recipient was one of the reasons cited by the participants for their opposition to directed donations that result specifically from public solicitation for organs. Like various authors (11,16,18,21,24,27), the participants believed that allowing solicited donations would give patients who are better equipped
to advertise their need an unfair advantage to obtain organs. Similarly, one of the participants shared Kluge’s view that media pleas (or other public pleas) for organs are misleading in that they highlight the need only of a single patient, thereby disregarding the needs of all the other patients (18).

The participants, however, also expressed views – that did not appear in the literature – against solicited donations. Recall, for example, that several of the participants regarded public appeals with suspicion because of their supposed tendency to misrepresent the patient’s true circumstances in hopes of attracting donors. As well, recall that some of the participants were concerned that solicited donations, if sanctioned, might occur in such large numbers as to significantly erode the equity of the waiting list.

Another important parallel was that, like many of the authors, the participants were generally opposed to directed donations in which the designated recipient is a member of a particular and identifiable group (11,16,17,19,24-26). The authors and the participants appeared to share the belief that it is unfair to make distinctions in the treatment of different categories of recipients, particularly on grounds of ethnicity, gender, religious faith, sexual orientation, or other discriminatory or prejudicial characteristics.

Similarly, recall that the participants believed that it was unethical to allow a family to restrict organs from going to recipients whom they believed to be personally responsible for their illness. The British Transplant Society appeared to be one of only a few authors who have written specifically about this type of directed donation (donations that
exclude recipients with alcohol-related disease), and their opinions about it corresponded with the opinions of the participants (20). Like the participants, for example, the British Transplant Society (implicitly) considered it unfair to exclude patients based on their past harmful actions, and further stressed the importance of informing families that “these patients go through a very rigorous assessment process designed to make the chance of recidivism very remote” (p.1536) (20). The only view that the participants articulated that the British Transplant Society did not, was that personal responsibility for one’s sickness cannot be accurately attributed, primarily because of the complex range of factors that may contribute to one’s illness.

The participants, like some of the authors (11,30), were also opposed to the LifeSharers initiative. Like Zink et al., many of the participants believed it was unfair to give members of LifeSharers priority access to organs. Further, like Murphy and Veatch (30), many of the participants objected to LifeSharers on grounds that not everyone would have an equal opportunity to become a member (e.g., some may not even know that LifeSharers exists). On the other hand, recall that a few of the participants, though still against LifeSharers, expressed sympathy with what they considered to be the organization's attempt to promote reciprocal responsibilities. Similarly, LifeSharers' co-founder, Undis, implicitly held such reciprocal responsibilities to be part of the ethical basis for the organization (32).

As well, like some of the authors (20,24,25), a small minority of the participants were in favour of allowing directed donations to children, primarily as an exception to the rule against group-based donations, but the rationales that each group offered were
different. Recall, for example, that a few participants believed that allowing donations to children would be consistent with the priority already given children in the standard allocation system (in Ontario), or that the long-term impact of organ disease was greater for children compared to adults. By contrast, as mentioned above, some authors argued that children have a limited opportunity to receive organs because the supply of children compatible organs is considerably smaller than the supply of adult compatible organs (20), or that children need organs to live a minimal lifespan (24), which adults have already achieved.

Another similarity was the belief, held by many of the participants and some of the authors, that allowing directed donations might weaken the trust that patients and the public have in the transplant community to distribute organs fairly. Similar to Pennings (19), several of the participants were concerned that a loss of trust might decrease the public’s willingness to donate organs, and thereby undermine the success of the entire transplant system.

**Implications for practice**

As I indicated at the beginning of this thesis, one of the aims of this study was to provide Trillium with information for use in further considering how best to govern directed donations. In particular, this study provided a range of practical and ethical considerations that a group of Ontario transplant professionals considered relevant, important and even necessary in assessing the acceptability of directed donations. Further, I have identified some of the circumstances under which these transplant
professionals thought that a donor, or the donor’s family, should be allowed to choose the recipients.

In summary, the transplant professionals generally believed that it would be important (in no particular order of priority) to: 31

1. Ensure that a directed donation satisfies all the medical requirements for a standard donation.

2. Educate the donor's family about the practical and ethical aspects of organ donation as part of obtaining the family’s informed consent to donate.

3. Educate the recipient about the psychosocial risks involved in receiving a directed donation as part of obtaining the recipient’s informed consent to receive such a donation.

4. Give priority to a medically urgent recipient over a designated recipient who is in less critical need.

5. Allow a directed donation if the designated recipient has a genetic or close emotional relationship with the donor, or the donor’s family, for example, a family member or a friend.

6. *Not* allow a directed donation if the designated recipient does not have a genetic or close emotional relationship with the donor, or the donor’s family,

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31 It is important to point out that this summary of the participants’ views is based on the views of the majority of the participants. This summary does not capture, for example, the few participants who were completely opposed to directed donations, or the few participants who believed it was acceptable to designate unrelated recipients. As such, this summary does not represent the views of all of the transplant professionals interviewed. My decision to present the views of the majority is not intended to suggest that such views are in any way more justifiable or well-considered, but rather, that such views had received broader acceptance.
for example, a recipient whose need becomes known through a public appeal for an organ.

7. *Not* allow a directed donation if the designated recipient is a member of a particular and identifiable group of recipients, for example, non-alcoholics, or members of LifeSharers.

The question, “How should Trillium respond to directed donations in light of these transplant professionals' views?”, defies a simple answer. On the one hand, from a deliberative democracy standpoint, there is a need for Trillium to take into account the perspectives of relevant stakeholder groups such as Ontario transplant professionals in an attempt to make ethically sound policy decisions. Doing so contributes to the legitimacy of the policy-making process and its outcomes, because stakeholders are afforded an opportunity to participate – directly or indirectly – in decisions that will affect them. Giving weight to the views of stakeholders is especially important when the policy issue debated is, like that of directed donations, one about which people have considerable differences of opinion, as well as where there appears to be no independent criterion for what is right or wrong. Ontario transplant professionals are an important, knowledgeable and articulate stakeholder group on matters of organ donation and transplantation, and so their perspectives on directed donations merit careful consideration.

On the other hand, transplant professionals are only one stakeholder group in Ontario, whose views on directed donations reflect unique values and beliefs. The transplant professionals interviewed in this study almost certainly had ingrained beliefs about
health care and their commitments to patients that led them to unique answers about the acceptability of directed donations. Other stakeholder groups, with different values and beliefs, are bound to have different opinions and concerns about the issue compared to those of transplant professionals. For that reason, the perspectives of other Ontario stakeholder groups, for example, policy-makers, the general public, other health care professionals (particularly those in the critical care community), as well as potential recipients and their families should be elicited and then compared with each other on the basis of their similarities and differences. This would assist in finding a way to govern directed donations that reflects, as far as possible, a balance between the interests of diverse stakeholders.

As well, the aim of this study was to explore and describe the transplant professionals’ views, not to evaluate, at least in a philosophically rigorous manner, the moral strength and rationality of such views. Such an evaluation remains to be done, and would further impact on the weight Trillium should give to the transplant professionals’ views.

An important normative question to explore more carefully is whether – as the majority of the transplant professionals believed – it is only justifiable to allow a directed donation if the donor, or the donor’s family, has a genetic or close (or “pre-existing” or “long-standing”) emotional relationship with the designated recipient. Hilhorst, for instance,

32 It is interesting to note that the notion that we are justified in favouring those who are close to us dates back to the ancient philosophers, Plato and Aristotle, who wrote about love and friendship as higher order virtues. Centuries later, Hume expounded the concept of partiality and gave it central importance in his moral philosophy. In A Treatise of Human Nature, he wrote: “Now it appears, that in our original frame of mind, our strongest attention is confin’d to ourselves; our next is extended to our relations and acquaintance; and ’tis only the weakest which reaches to strangers and indifferent persons. This partiality, then, and unequal affection,
argued that the special felt loyalties and commitments that a donor has toward certain designated recipients, and which he believes justify the donor’s partiality for them, may extend beyond family members and friends, to distant others with whom he or she sympathizes or identifies on a personal level (22). According to this view, partiality would not necessarily require for its justification a close or long-standing relationship between a donor and designated recipient.

In the baby Kalyee case described above, Kaylee’s parents’ decision to seek out baby Lillian’s parents and offer to donate their child’s heart to Lillian may well have been motivated by their sympathetic concern for Lillian and genuine understanding of Lillian’s parents’ intense suffering over their dying daughter. Should Kaylee’s parents’ emotional response to Lillian and her parents count for less simply because the former parents learned of Lillian’s need in the Toronto Sun, or because the bond that both infants’ parents claimed to have developed after meeting each other was only days old? It is not clear whether the circumstances under which Kaylee’s and Lillian’s parents came to know each other, or how long they knew each other, are really so important in judging whether Kaylee’s parents’ emotional response to Lillian was morally significant enough to allow them to designate her as the recipient. The parents’ emotional response seemed deeply and strongly felt even though it did not arise in the context of a close or long-standing relationship with Lillian or her parents. The view, then, that having such a

must not only have an influence on our behaviour and conduct in society, but even on our ideas of vice and virtue...This we may observe in our common judgements concerning actions, where we blame a person, who either centers all his affection in his family, or is so regardless of them, as, in any opposition of interest, to give preference to a stranger, or mere acquaintance”. See: Hume D. A treatise of human nature. 2nd ed. New York: Clarendon Press; 1978. pp.488-489. Hume justified partiality based upon what is natural in human nature. He argued that unequal affections toward family, friends, acquaintances, and strangers are morally significant and provide grounds for our conception of vice and virtue. See: Coleman D. Partiality in Hume's moral theory. Journal of Value Inquiry 1992 Jan;26(1):95-104.
relationship is a moral prerequisite for directing the donation of an organ needs further ethical justification.\textsuperscript{33}

A related problem arises when attempting to enforce such a moral prerequisite. Practically, there is no precise way to verify the emotional depth and closeness of personal relationships. Some authors have proposed that donors and designated recipients be made to present legal proof of their relationship, for example, marriage certificates or affidavits (11). One can imagine similar requirements, for example, providing photographs of past times shared between the designated recipient and the donor, or the donor's family, or – as is often done in \textit{living} organ donation – undergoing psychiatric assessment to ascertain the nature of the relationship between the potential donor and recipient. Any of these or similar requirements would be difficult to satisfy given that, in deceased organ donation, there is usually only a small window of time in which such evidence could be obtained. Further, such requirements may be viewed as trivial or even offensive to someone in a state of trauma and deep sadness over the death of a loved one.

One can almost certainly see why a careful ethical evaluation of the transplant professionals' views should be undertaken. In the meantime, it would be beneficial to consider their views in combination with those of authors in the literature. The many commonalities between the two groups' views, described above, give such views a

\textsuperscript{33} To be sure, some moral philosophers believe that partiality is most, or is solely, justified in relationships based on enduring, interpersonal, emotional contact between the participants. See for example: Friedman M. The practice of partiality. Ethics 1991;101(4):818-835. These philosophers, I believe, would say that mere directed feelings of well-being for designated recipients whom one barely knows, and with whom one has no shared history of deep emotional interaction, fail to justify one's preferences for them.
certain amount of reinforcement. The commonalities do not prove the views right or wrong, but indicate a broader acceptance of their importance. The differences between the two groups’ views are also important in that they illustrate different ways of thinking about the issue. The transplant professionals, for example, raised several matters of importance to the issue of directed donations that had not, or had only superficially, been discussed by the various authors in the literature.

Trillium may be the direct beneficiary of this study – to have heard from key informants within its own jurisdiction – but other members of the transplant community within Canada and abroad may find the views of these Ontario transplant professionals useful for their own purposes. Maybe they are academics who are interested in directed donations primarily from a theoretical standpoint, or government authorities who are wrestling with policy options to govern directed donations, or transplant coordinators who are looking for guidance on dealing with future requests from families to designate the recipients. The views of the transplant professionals described above have helped at least to inform the debate on directed donations. A bit more enlightenment on a complex topic, particularly on issues that had not received much prior attention, is not a bad thing.

Limitations of this study

This study had several limitations. First, as I mentioned above, this study’s sample of participants cannot be confidently generalized to a larger population of transplant professionals. The goal of using a small, purposeful sample was to obtain a deeper understanding of the transplant professionals’ views about directed donations. The
sample was designed to seek *depth* and not *breadth* of information. This limitation should be borne in mind when making any extrapolations based upon the results.

Second, the participants sampled were from a single transplant centre in Ontario, and so their views about directed donations may have been partly shaped by the values embedded within the transplant policies and practices of that particular institution. It seemed, for example, that some participants would occasionally use their transplant centres' established practices as the benchmark for judging actions right or wrong with respect to directed donations. Had the participants been selected from a different transplant centre (e.g., a centre with a different internal mission, standards, types of donations and transplantations, etc.) their views might have varied accordingly. For this reason, if I were to do this study over again, I would recruit transplant professionals from more than one transplant centre, and note any significant differences among the views expressed which may have resulted from the particular experiences of the transplant professionals at a particular institution (e.g., differences that may be tied to local knowledge, practice, organizational culture, etc.).

Third, my decision not to identify the institution at which the participants worked (which was intended as a measure to protect their privacy and confidentiality) limited my ability to provide contextual information about the institution (e.g., the institutional characteristics mentioned above). This, in turn, limited my ability to provide interpretations of the participants' views that may have been influenced by such characteristics.
Forth, the participants' responses were largely unprepared and off-the-cuff. Some of the participants stressed that they had not given the acceptability of directed donations much consideration. I encouraged the participants to think more deeply about directed donations by having them reflect on various permutations of such donations, to respond to alternative viewpoints, and to explain the bases for their responses, but, despite these efforts, their responses may have been different had they thought longer and harder about the issue. Several of the participants, for example, modified their lines of reasoning at different points throughout the interview, as they developed a greater appreciation of the factors impacting directed donations. As such, it cannot be taken for granted that the views expressed by the participants about directed donations in this study represent their final thoughts on the subject.

Fifth, it is difficult to measure what, if any, influence the particular subtle details of the hypothetical scenarios (e.g., the type of organ, the length of time the designated recipient had been waiting for an organ, the circumstances around the donor's death, or details containing social or emotional elements) had on the participants' responses. It is possible, for instance, that some of the participants looked favourably upon the family's request to direct the son's organ to his father (in scenario one) because of the unique importance society places on father-son relationships. Would these participants have felt differently if the designated recipient was not the son's father, but his aunt, or second cousin? It is, however, important to point out that the participants tended not to dwell on the finer details of the scenarios. Instead, they usually almost immediately abstracted from the specific scenarios to the general categories of directed donations that they represented. The participants would say, for instance, “...well, here you’re
talking about donations to family, so my general feeling would be that…”, or “…this scenario is different…because the recipient is unrelated to the donor family”, or “Okay, I see, the donation is to a group, not a specific individual. In this case, this is not something I would support…” Based on these observations, my view is that the extent to which the finer details of the scenarios may have shaped their responses was probably quite limited.

**Conclusion / Future research**

As I mentioned above, from the standpoint of governing directed donations in Ontario, it would be helpful to learn what other stakeholder groups in the province think about the issue. Eliciting the views of policy-makers, the general public, other health care professionals (especially those in the critical care community), as well as potential recipients and their families would help in finding a way to govern directed donations that balances, to the extent possible, the diverse interests of multiple relevant stakeholders. Further, if various authors and the transplant professionals interviewed are correct in their assumption that the success of the transplant system hinges in part on patients’ and the public’s trust that organs are being fairly rationed, it would be prudent to ask these groups how they feel about directed donations. Ultimately, an ethical analysis of the various stakeholders’ views would be important in helping to determine the normative weight of such views.

This study has, hopefully, demonstrated the advantages of using a qualitative approach to elicit people’s views on the subject. The qualitative approach permitted an understanding of the beliefs and assumptions behind the transplant professionals’
positions. I was able to learn why they felt that some directed donations were acceptable and others were unacceptable. Accordingly, I would recommend conducting a similar qualitative study of the views of the stakeholder groups mentioned above. For a start, one could elicit the groups’ responses to the hypothetical scenarios used in this study and, in doing so, produce a wealth of in-depth information about their perspectives on the issue. This approach would also allow one to assess the extent to which the views expressed were based on accurate information and reasonable moral judgements.

Once this qualitative exploration has been completed, it would then be beneficial to conduct statistically representative studies of the views of each of the stakeholder groups. Such studies would make it possible to measure, in theory, what each group as a whole thinks about directed donations. According to Charmaz, qualitative studies offer the grist for quantitative studies to pursue later (50). That is, the categories of significance that emerge inductively in qualitative studies can then be used in quantitative studies to test their degree of importance across a broader population of people. The point is that the findings of quantitative studies are more credible if their categories of analysis have an empirical foundation, which qualitative studies help provide. The results of this study, therefore, can be used to develop measurement scales that are more closely based upon that which Ontario transplant professionals actually believe to be important about directed donations.
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APPENDICES

Appendix A: Letter of invitation to participate in study

Dear Participant,

I would like to introduce you to a study being conducted by Kelley Ross, an MSc student at the University of Toronto in the Department of Health Policy, Management, and Evaluation.

For his thesis project, Kelley is working with Professor Barbara Secker, University of Toronto, to explore the opinions of transplant professionals in Ontario about directed organ donations from deceased donors.

The title of the study is “Interviews with Transplant Professionals in Ontario about Directed Organ Donations after Death”. This study was approved by the hospital’s Research Ethics Board and by _, in January 2009. I am the hospital’s on-staff supervisor for this study.

Kelley is interested to explore opinions on the question: “Under what circumstances, if any, should a person, or his or her family, be permitted to direct organs to a particular designated recipient (e.g. a relative, friend, or person identified through a public plea for organs) or designated group of recipients (e.g. children, a member of an identified group)?”

Currently, in Ontario, there is no formal policy to govern directed donations from deceased donors. The results of this study may provide transplant policy-makers in Ontario with information for use in considering how to respond to directed donations.

Kelley is hoping to speak to 8-12 people from different professions across the Program. Accordingly, I have helped Kelley identify an initial group of invitees. The interview will seek participants’ general thoughts about hypothetical scenarios involving directed donations. No previous knowledge about directed donations is needed. The identity of and information provided by participants will be strictly confidential and known only to Kelley. Kelley alone will have access to any data that can be directly traced to individual participants.

We are inviting you to consider participating in this study on directed donations from deceased donors. Participation is completely voluntary. Kelley is copied on this e-mail. He will contact you to follow up within the next week.

If you would like more information or have questions about this study, please do not hesitate to contact Kelley at (416) 828-6035 or kelley.ross@utoronto.ca, or his thesis advisor, Barbara Secker, at (416) 978-1909, Monday to Thursday 9AM to 5PM.

34 References to information that might identify the institution where the participants worked have been omitted to safeguard the participants’ anonymity.
Thank you for allowing me to introduce this study to you.

Sincerely,

[Signature]
Appendix B: Letter of information and consent form

CONSENT FORM FOR PARTICIPATION IN RESEARCH

Study Title: Interviews With Transplant Professionals in Ontario about Directed Organ Donations After Death

Investigators:

<table>
<thead>
<tr>
<th>(On-staff supervisor)</th>
<th>Mr. Kelley Ross (Primary contact person)</th>
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<tr>
<td>Ms. Linda Wright</td>
<td>MSc student</td>
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<tr>
<td></td>
<td>Department of Health Policy, Management and Evaluation, Faculty of Medicine</td>
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<td></td>
<td>University of Toronto</td>
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<td></td>
<td>88 College Street</td>
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<td>Toronto, Ontario, M5G 1L4</td>
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<td></td>
<td>Telephone: 416-340-4800 x 8750</td>
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<td>Available Monday to Friday, 9AM-5PM</td>
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| Ms. Barbara Secker    | Dr. Ross Upshur                         |
| Assistant Professor   | Associate Professor                     |
| Department of Health Policy, Management and Evaluation, Faculty of Medicine | Department of Family and Community Medicine and Public Health Sciences |
| University of Toronto | University of Toronto                   |
| 88 College Street     | 88 College Street                       |
| Toronto, Ontario, M5G 1L4 | Toronto, Ontario, M5G 1L4 |
| Available Monday to Friday, 9AM-5PM | Available Monday to Friday, 9AM-5PM |

You are being asked to consider taking part in a research study that explores the views and opinions of transplant professionals in Ontario about directed organ donations after death. Your opinions and views on this issue are valuable and are being sought for the purposes of this study. Approximately 8-12 people from different professions across the Multi-organ Transplant (MOT) Program at University Health Network (UHN) will be asked to consider participating in this study.

This study is being conducted as part of Kelley Ross’s thesis project. Mr. Ross is a Master’s student in the Department of Health Policy, Management and Evaluation at the University of Toronto. His thesis advisor is Barbara Secker (Assistant Professor at the University of Toronto) and his thesis committee members include Ross Upshur (Associate Professor at the University of Toronto) and Frank Markel of Trillium Gift of Life Network (TGLN). Mr. Ross is the primary contact person for this study. The on-staff supervisor/investigator for this study is [Redacted].

Please read the information below explaining the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask Mr. Ross or Ms. Secker to explain anything that you do not understand, and make sure that all of your questions have been answered.

35 References to information that might identify the institution where the participants worked have been omitted to safeguard the participants’ anonymity.
before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is completely voluntary.

**What is this study about?**
Ontario’s organ and tissue donation agency, Trillium Gift of Life Network (TGLN), allocates the organs of deceased donors to those recipient candidates who are ranked highest on the provincial waiting list for transplant surgery. Priority for organs is based on several criteria, including a recipient’s medical need and the likelihood of a successful transplantation. Occasionally, however, a donor, or his or her family, will request or stipulate that an organ be given to a particular designated recipient or designated group of recipients (a “directed donation”).

Currently, in Ontario, there is no formal policy to govern directed donations. This study will explore the views and opinions of transplant professionals in Ontario about the acceptability of directed donations. The results of this study may provide transplant policymakers in Ontario with information for use in considering how to respond to directed donations.

Transplant professionals are one of several stakeholder groups in Ontario whose views and opinions about directed donations are important to know. Your active involvement in the delivery of transplant services in Ontario, combined with your specialized knowledge and experience in transplantation, make you well-suited to share your views and opinions about directed donations. We would like to include you as one of 8-12 transplant professionals to be involved in this study.

**What does participation involve?**
Participation in this study will involve a one-on-one, semi-structured interview with Mr. Ross of approximately 30-60 minutes in length. If you choose to participate, you will be asked to share your general thoughts about different hypothetical scenarios involving directed donations. No previous knowledge about directed donations is necessary.

With your permission, the interview will be audio recorded to facilitate the collection of data. Also, with your permission, broad demographic information (e.g. sex, age range) and work-related information (e.g. years of experience in health care, years of involvement in transplantation) will be collected. This information may be used to contextualize the research findings and to aid data analysis. Following the interview, you may be contacted if clarification on your feedback is required. The interview will take place at a time and location most convenient to you.

**What are the risks and benefits of this study?**
There is a possibility that you may feel uncomfortable being asked questions about directed donations if the subject of religion or race should arise. We would like to assure you that you will not be asked to share your personal experiences about religion or race, but rather, your opinions from a policy standpoint about whether people should be permitted to attach conditions to a donation based upon the religion or race of a recipient group. The section describing your rights as a participant (below) lists further protections against the risk of feeling uncomfortable.

You may also be concerned that your decision to participate may impact your future employment at UHN. We would like to assure you that your participation or non-participation will have no effect on your professional or personal life. None of the investigators except for Mr. Ross will know who participates, unless the participants choose, of their own free will, to tell them or anyone else. No UHN staff members, Linda Wright, will have access to interview transcripts.
Apart from the opportunity to share your opinions about directed donations, there are no direct benefits to you as a participant in this study. However, as mentioned above, the results of this study may provide transplant policy-makers in Ontario with information for use in considering how to respond to directed donations. As well, this study may help inform the ongoing debate about directed donations in the broader transplant community. There is no compensation for participation in this study.

**What about issues of privacy and confidentiality?**

All information you provide will be considered completely confidential. A unique number code will be used in lieu of your name and the name of your organization for the identification of audio recordings, interview transcripts and notes. Audio recordings of the interviews will be transcribed for the purpose of data analysis, and once checked for accuracy, immediately destroyed. Mr. Ross alone will transcribe the interviews.

Any data containing personal information, both in digital or paper form, will be kept confidential and stored and locked in a secure area. Only Mr. Ross will be authorized to retrieve this information. Any data stored on computers will be de-identified, and the computers on which the data are stored will be password-protected and remain in locked and secure areas.

Only Mr. Ross will have access to data that can be traced to individual participants. This means that, while select investigators—Mr. Ross, Ms. Secker and Dr. Upshur—will have access to interview transcripts to assist with data analysis, only Mr. Ross will be able to determine which transcripts belong to which participants. As indicated above, only Mr. Ross will know who participates in this study, unless a participant chooses, of his/her own free will, to tell the investigators or other people. No other person will have access to your personal or other identifying information, unless required by law.

Neither your name, the name of your organization, or other information that directly identifies you, will appear in any thesis, report, publication, or presentation that may come of this study; however, with your permission anonymous quotations may be used. Any publication that comes of this study will be provided if you so wish.

It is important to understand that despite the above protections being in place, there is always the risk that confidential information could be unintentionally released. The risk that such information will be accidentally released is small.

By signing this consent form, you are authorizing access to your data by the study investigators, [redacted] and government regulatory authorities (e.g. Health Canada). The latter two bodies’ access to the data would be solely for the purpose of verifying the authenticity and accuracy of the information collected for the study, without violating your confidentiality to the extent permitted by applicable laws and regulations. In no way does signing this consent form waive your legal rights, nor release the investigators or the involved institutions from their legal and professional responsibilities.

The Protection and Electronic Documents Act (PIPEDA) and the Personal Health Information Protection Act (PHIPA) protect your personal information. They also give you the right to control the use of your personal information and require your written permission for this personal information to be collected, used, or disclosed for the purposes of this study, as described in this consent form. You have the right to review and copy your personal information collected in this study. This information would be in the form of raw data (e.g. interview transcripts). However, if you decide not to be in this study or choose to withdraw from it, your right to look at or copy your personal information related to this study will be delayed until after the research is completed.

Study data will be retained for a maximum of three years, after which it will be destroyed in a secure manner.
**What are your rights as a participant?**

Participation in this study is completely voluntary. No information about your decision to participate or not to participate will be communicated up (or down) the hierarchy of your institution. You can refuse to answer any interview questions, to skip questions by saying “pass”, and to conclude the interview at any time. Further, you may decide to withdraw from the study at any time, without any negative consequences, by advising Mr. Ross or Ms. Secker. Your withdrawal will have no effect on your future employment at [insert institution name]. If you choose to withdraw, data obtained up to the point of withdrawal may be included in the study. Any information that is learned during the study that might affect your decision to stay in the study will be provided to you. You have the right to access the information you provide during the interview.

**Who can I contact for further information?**

If you have any questions, concerns or would like to speak to the study team for any reason, please contact Mr. Ross at (416) 828-6035 or kelley.ross@utoronto.ca, or Ms. Secker at (416) 978-1909 or barbara.secker@utoronto.ca.

If you have any questions about your rights as a research participant or have concerns about this study, contact Research Ethics Board (REB). The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

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**CONSENT FORM FOR PARTICIPATION IN RESEARCH**

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

I agree to have my interview audio recorded. □ YES □ NO

I agree to the use of anonymous quotations in any thesis and/or publications that comes of this research. □ YES □ NO

Print Study Participant’s Name ___________________ Signature ___________________ Date __________

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent ___________________ Signature ___________________ Date __________

Was the participant assisted during the consent process? □ YES □ NO
If **YES**, please check the relevant box and complete the signature space below:

☐ The person signing below acted as a translator for the participant during the consent process and attests that the study as set out in this form was accurately translated and has had any questions answered.

_________________________  ________________  __________
Print Name of Translator                 Signature                 Date

_________________________  __________________________
Relationship to Participant                     Language

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

_________________________  ________________  __________
Print Name of Witness                 Signature                 Date

_________________________
Relationship to Participant
Hypothetical scenarios

(The participants were given a copy of the hypothetical scenarios in the format below.)

1. A young man has died in a car accident on the way home from a skiing trip in northern Ontario.

   His father, who suffers from cardiovascular disease, has been on the waiting list for heart transplant surgery for two years.

   The young man’s family has agreed to donate their son’s organs, but has requested the heart be given to the father.

2. A middle-aged woman was struck by a car while jogging along a sidewalk in Toronto and suffered a fatal head injury.

   Her husband has a childhood friend who suffers from chronic liver failure and has been waiting for a liver transplant for over a year.

   The husband has agreed to donate his wife’s organs, but only if her liver is given to his childhood friend.

3. A middle-aged woman with renal failure has been on Ontario’s waiting list for a kidney for over four years.

   A couple of days ago, she advertised her need in a local newspaper in the hope of finding a donor. Her children also distributed flyers and created a webpage called www.SaveMomsLife.com.

   A young man has just died in the hospital from a cerebral haemorrhage. His family, who had been touched by the woman’s emotional appeal in the newspaper, has stipulated that their son’s kidney be given to the woman.
4. An elementary school teacher has been involved in a bicycle accident and dies at the hospital.

Her husband has agreed to donate her organs, but requests that, as far as medically possible, the organs be given to children.

He claims his wife had devoted her life to children, and so she had always wanted her organs to benefit children.

5. A middle-aged man has died from a cerebral haemorrhage. He carries an unusual donor card. It states, "Please give my organs, first, to members of LifeSharers, unless no suitable match can be found."

The card explains that LifeSharers is a donor organization whose members all agree to donate organs after death, but to give priority access to other members.

LifeSharers can be contacted at a number on the card for information about other members in need.

6. A teenaged man has suffered a fatal head injury during a hockey game at a Toronto arena.

His parents are eager to donate their son’s organs so that he may “live on in others”, but stipulate that the organs be restricted from going to patients whose illness resulted from drug or alcohol abuse, or who are otherwise personally responsible for their illness.

The parents explain that such patients do not deserve their son’s organs.

Standard questions

- “Imagine that you are one of the people responsible for allocating organs in Ontario.

Describe what you think should be done”. (This question was repeated for each of the scenarios.)
• “How would you explain the differences in your responses between scenario ‘X’ and scenario ‘Y’?”
• “Are there any circumstances under which you feel that a directed donation should be accepted?”
• “Are there any circumstances under which you feel that a directed donation should not be accepted?”
• “Is there anything that we haven’t talked about that you would like to share with me?”

Probing questions

• E.g. “How would you explain your response that donations to groups of recipients would cause more harm than benefit?”
• E.g. “One of the views in favour of allowing directed donations is that organs are personal property, and so people should have control over how they are used. How would you respond to this view? (These types of questions varied depending on the participants’ general views on directed donations, but the goal was to elicit their responses to opposing or alternative views.)