

2014

The Deserving And Undeserving: Examining Ontario's New Strategy For Organ And Tissue Donation

Colleen M. Connors
Wilfrid Laurier University

Follow this and additional works at: http://scholars.wlu.ca/brantford_sjce



Part of the [Community-Based Research Commons](#), and the [Medicine and Health Commons](#)

Recommended Citation

Connors, Colleen M., "The Deserving And Undeserving: Examining Ontario's New Strategy For Organ And Tissue Donation" (2014). *Social Justice and Community Engagement*. 3.
http://scholars.wlu.ca/brantford_sjce/3

This Article is brought to you for free and open access by the Laurier Brantford at Scholars Commons @ Laurier. It has been accepted for inclusion in Social Justice and Community Engagement by an authorized administrator of Scholars Commons @ Laurier. For more information, please contact scholarscommons@wlu.ca.

THE DESERVING AND UNDESERVING:
EXAMINING ONTARIO'S NEW STRATEGY FOR ORGAN AND TISSUE DONATION

Colleen M. Connors ©

International Studies, Canadian University College, 2013

Submitted to the Social Justice and Community Engagement Program

in partial fulfillment of the requirements for

Master of Arts in Social Justice and Community Engagement

Wilfrid Laurier University

2014

ABSTRACT

The medical marvel of organ and tissue transplantation has spurred new questions about the divisible body and its potential for commodification, dividing the world into unequal populations—receivers and donors. Efforts to foster equilibrium in the supply and demand of transplantable organs have led many to argue for market-based solutions; however the role of privilege has often been made invisible in these discussions, exacerbating pre-existing global inequalities. This paper acknowledges Canadian patient engagement in systems of organ trafficking, and explores the current strategy enacted by Trillium Gift of Life Network (TGLN) to improve organ and tissue donation and transplantation (OTDT) in Ontario and its potential to mitigate transplant tourism. Using an institutional ethnographic approach, the focal point of this research is an examination of the primary texts produced by TGLN. Proposals supporting a legal market for organs are also addressed, including their conflict with the Canadian Medicare system, which was established to prevent the allocation of health care services based on ability to pay. Significantly, TGLN upholds this principle and emphasizes the value in altruistic donation and decommodified approaches to OTDT. If successful, TGLN could lead the way for improving systems of OTDT in Canada. However, concerning themes have been identified which can be understood as barriers to the success of TGLN and thus impede its efforts to increase donation, develop adequate infrastructure with which to effectively procure and allocate organs and tissues, and reduce incidence of Canadian patient participation in transplant tourism.

Acknowledgements

I would like to express deep gratitude to my research advisor, Dr. Rebecca Godderis, for her valuable guidance, enthusiastic encouragement, and constructive suggestions during the planning, writing, and editing process of this project. Her time, dedication, and immense knowledge have been very much appreciated.

A very special thank you to Dr. Janet McLaughlin, whose advisement and support during the formulation of this research project was of incredible help.

In addition, I would like to thank the other member of my committee, Dr. Monir Moniruzzaman, who generously agreed to be a part of my project and whose academic work helped informed significant parts of this major research paper.

Finally, I would like to thank my parents, John Connors and Dianna Connors, for their unending support of and confidence in me; and my partner Dominic Fabrig, for everything.

TABLE OF CONTENTS

I. INTRODUCTION	1
II. LITERATURE REVIEW	9
Repugnance and the Efficiency of the Market	9
Autonomy of the Body: The Right to Sell Yourself	11
The Morality of the Market	13
Privilege, Poverty and Moral Imperatives	16
Canadian Responses to Transplant Tourism and the Organ Crisis	18
III. METHODS	22
Theoretical Approach	22
Research Design	26
Data Sources, Parameters, and Collection Techniques	27
Data Analysis and Interpretation	30
Ethical Considerations	31
IV. RESULTS	31
Routine Notification for Designated Hospitals	32
Routine Notification Worksheet	40
Next Steps Worksheet	45

Frequently Asked Questions for Healthcare Professionals	46
V. DISCUSSION	51
Gatekeeping	52
Positivity	54
Processes of Othering	58
VI. CONCLUSION	67
References	74
Appendix: Trillium Gift of Life Network Texts	82

I. INTRODUCTION

The transplantation of organs and tissues from living or cadaveric donors as a means to save or prolong human life was like science fiction come to life during the 1960s, a decade that witnessed the first liver, lung and heart transplants, all standard procedures today (Price, 2000, p. 23). Advances in transplant technology have made it possible for approximately thirty different organs and tissues to be extracted for transplantation purposes (Banks, 1995, p. 46). However the medical marvel of organ transplantation was spread thin as demand swiftly overtook supply. Price (2000) reflects that the swelling increase in the demand for organ replacement therapy has made certain that in nearly every country in the world, there is a shortage of available organs for transplant (p. 23). However, E. Bailey (1999) reframes the problem, explaining that there is not actually a shortage of organs, “but a lack of adequate infrastructure to support an effective organ donation system” (p. 10).

The 1960s marked the formative years of transplantation, and with it, transplantation ethics (Price, 2000, p. 23). An early challenge for policymakers and the medical community, which still persists today, was in creating and sustaining a more effective system of transplantation to match the growing demand. Meanwhile, an international organ trafficking syndicate developed in the underground. Shimazono (2007) identifies organ trafficking as a consequence of “the incapacity of national health care systems to meet the needs of patients with the lack of appropriate regulatory frameworks or implementation elsewhere.” The black market for organs has become a flourishing industry, generating half a billion dollars each year by

conservative estimates. To put this into context, the World Health Organization reports that one human organ is sold illegally every hour (Shimazono, 2007).

The medical marvel of organ and tissue transplantation has spurred excitement and discussion beyond its promising potential to save, enhance and extend human life. Significant new ethical questions have emerged surrounding the relationship between autonomy of the body, privilege and poverty, 'gift relations' and 'gift theory', the limits of commodification, and who is deserving of the organs biomedical science has allowed us to transplant. Although advancements have been made in xenotransplantation (transplantation from another species; in this context, animal-to-human), and with the use of mechanical organs, humans still remain the most successful and preferred source of organs (Sharp, 2001, p. 116). Scientists are currently experimenting with the potential of cloning human organs and with stem cell research which could allow for organ regeneration. While promising, these ideas are not expected to be viable alternatives anytime soon (Beltrami et al., 2007, p. 3445).

Once a precarious and doubted medical experiment, organ and tissue transplantation is now commonplace in Canada and many other countries the world over. Canada's universal healthcare policy makes it a particularly interesting country to consider in the ongoing debate on the ethical implications of transplant practices. As demand for organs swiftly outpaces supply across the developed world, a growing number of patients are dying on wait lists that have become years-long. Meanwhile, an international organ trafficking syndicate developed in the underground as governments struggled to manage the burgeoning demand. In light of this, the proposition to legalize a market for organs is gaining unprecedented support in current debates.

Altman (1994) insists that “there needs to be a universally accepted system for organ donation because if one country deviates, the black market will continue” (p. 181).

It is worth exploring the possibility that the demand for organs may never be met, and furthermore, that this may be a consequence of the system itself. There is a relationship between the “organ shortage” (or the inability of health care systems to successfully allocate organs) and invented scarcity. Cooper (2008) discusses the bilateral workings of the Deleuze and Guattari-referencing “capitalist delirium,” the desire to both exceed limitations while simultaneously reinstating them through the creation of scarcity. These motives are mutually constitutive, Cooper argues (p. 49). Cooper also expands on Marx’s musings of the inimical tensions of capitalism by addressing these concerns in the modern context. Today, such tensions interact on a biospheric scale that stretches across the world in the form of globalization, and as such, bears serious implications for all of humanity’s future (Cooper, p. 49). The mechanisms of capitalism in this understanding are such that in order for the wheel to keep turning, new incarnations of scarcity are fabricated and embedded into the assurance of a ‘bioregenerative’ economy (Cooper, p. 50). Once the figures which could be identified today have been realized in order for supply to meet the demand for organs, this satisfied demand will give way to more demand, and supply will yet again be lagging behind. Thus, the “organ shortage” becomes a necessary constituent of the modern capitalist society, and the perpetuation of this invented scarcity is in the best interests of a system in which organs are commodified.

The fabrication of scarcity in the culture of biomedicine partly relies on the human quest for immortality. Illich (1974) draws upon Greek mythology to explain what he calls the “counter-intuitive misadventures” which are the peculiarities of industrial society (p. 920). The myth

details an act of thievery by Tantalus, a Lydian king, after he was invited to dinner on Mount Olympus by the gods, of which included his father, Zeus. There, he stole the magical nectar of everlasting life, Ambrosia. Angered, the gods punished Tantalus to live out his immortality in Hades, damned to the endless torture of hunger and thirst. This “craving for Ambrosia” has infiltrated the entire world, Illich contends; an addiction manifested through the optimism of the scientific and political realms (p. 920). The propagation of a seemingly limitless biomedical potential has coaxed a demand from people that their lives be enhanced and extended beyond all elements of aging and decay. “As a result,” Illich concludes, “health has become scarce to the degree to which the common man makes health depend upon the consumption of Ambrosia” (p. 920). In light of both Cooper (2008) and Illich’s (1974) theories, it can be postulated that invented scarcity is linked to aggressive organ procurement practices, and thrives in a biomedical culture that both demands growth and assumes intervention to prolong human life is always the ideal option.

Patients in Global North countries, Canada most certainly included, have lost faith in legal systems of transplantation’s ability to provide an adequate or timely resolution, leading some to engage in transplant tourism. This “alternative means” of obtaining organs and tissues is a package-deal purchase which includes round-trip airfare to a Global South country, an organ of choice (most commonly a kidney) brokered from a middleman, and transplantation surgery. This practice is intensely problematic and makes use of, and intensifies, preexisting global inequities. As prominent organ trafficking expert Scheper-Hughes (2003) explains, the flow of organs is not unlike other prevailing routes of capital, moving from North to South, from East to West, from female to male, from poor to rich, and from people of colour to those who are white (p. 1645).

For example, anthropologist Moniruzzaman (2012) has studied the devastating outcome of being a kidney seller in Bangladesh, detailing the long-term consequences, which are significant in terms of both physical bodies and social relations (p. 80). Post-surgery, sellers (not to be confused with brokers) have expressed crippling shame and social isolation. They also report both economic and bodily hardships, finding themselves in even worse circumstances than the one which motivated them to sell their kidney in the first place (p. 81).

Another pressing concern is that by purchasing organs via transplant tourism, these patients pose a threat to the stability of Canada's public health care system. Wright, Zaltzman, Gill, and Prasad (2013) observe that in the purchase of illegal organs, including cases of transplant tourism, patients with considerable financial means are able to "jump the cue for transplantation" (p. 923). This creates a system that, however unofficial, allows some relatively wealthy individuals to receive medical treatment in advance of others. This unequal access is antithetical to the what Health Canada calls the "basics" of Medicare, where services are allocated not on the ability to pay, but on the basis of need (Health Canada, "Health Care System").

The incidence of transplant tourism is rising, and the reason that is often cited for this is that it is a response to an "organ shortage," however transplant nephrologist Hippen (2008) reiterates Bailey's assertion that the organ shortage is not really an issue of supply and demand. He states this presumed "shortage" is actually the result of sweeping policy failures, not only in the systematic allocation and distribution of organs, but also in emphasizing the need for live and cadaveric donors to the public (Hippen, p. 1). Proposals to diminish and ultimately eliminate wait lists for organs have often looked to implement financial incentives for organ donation,

essentially taking the system currently at play in the black market and making it part of the private sector. In Canada, this would mean making the organ and tissue donation and transplantation (OTDT) system independent from the public health care system.

Canadians participate in this organs market as purchasers. Discouraged by the prospects of waiting on legal transplantation lists, where “almost every day and a half, [a Canadian patient] dies while waiting for an organ transplant,” (Sher as cited in *The Canadian Press*, 2012) travelling to a Global South country to purchase an organ from a trafficker may seem like the best chance at surviving end-stage organ failure. Upon return to Canada, these patients often face significant health complications requiring post-operation treatment from Canadian medical practitioners (*Call to Action*, 2011, p. 12). As Canada’s population ages, more and more organs will be in demand while the availability of transplantable organs stagnates; continuing advances in transplant technology will allow for a greater number of patients to benefit from transplant; and the rising rates of diabetes and Hepatitis C infection will result in higher instances of end-stage organ failure requiring transplantation for survival of the patient (p. 61). These factors will compound to put swelling pressure on a transplant community that already cannot meet current demands and will not be able to sustain burgeoning future demands. The incompetency of legal systems of transplantation in Canada may increasingly be a catalyst for transplant tourism and organ trafficking across the globe. It is for these reasons that the following research study focuses on the Canadian health care system and, more specifically, examines how the current approach in the Province of Ontario is addressing the need to improve OTDT through an organization called Trillium Gift of Life Network (TGLN). Examining TGLN’s strategy to improve the current OTDT system while preserving a decommodified approach will yield

insights into how to provide better health care to Canadian patients, and potentially (albeit indirectly) reducing their participation in transplant tourism.

The research problem I have identified is predicated upon several fundamental assumptions. Current systems of transplantation in Canada appear to be failing, and improvements to the current OTDT system will both significantly reduce the unnecessary deaths of patients on wait-lists in Canada and the unethical venture of transplant tourism by these patients. Within and beyond the transplant community suggestions for improving the present system have been widely proposed, but many advocate for a regulated market-based approach. These approaches are problematic. By allowing for the commodification of human organs and tissues Canada would be, in effect, legitimizing the black market for organs and conceding to a system that markedly divides the world into two types of people: receivers and sellers, receivers being motivated by sickness and sellers by poverty. A commodified approach also impedes the Canadian Medicare system which is predicated on allocating services according to need, not ability to pay. Furthermore, a legal market for organs detracts from a system based on altruism and its associated social benefits, something TGLN expresses great concern about, as will be discussed later in this paper.

In order to understand how improving the Canadian health care system could affect transplant tourism, I have decided to take an in-depth look at current Canadian systems and how they operate. My specific site will be Ontario's evolving OTDT system under TGLN. The focal point of this research will be to take a closer look at the primary texts produced by TGLN in order to shed light on the ways in which they coordinate and inform the actions of the healthcare professionals charged with carrying out the new legislation recently enacted at all Ontario

hospitals by TGLN. Addressing TGLN's approach to the challenges of organ and tissue donation in Ontario is one way of critically thinking about how to establish a more effective system throughout all of Canada.

When the Medical Care Act was introduced in 1966, then Canadian Minister of National Health and Welfare Allan J. MacEachen began his argument for its implementation declaring: "the government of Canada believes that all Canadians should be able to obtain health services of high quality according to their need for such services and irrespective of their ability to pay." However proposals to rectify the current incarnation of the Canadian OTDT system through a free-market system undermine the intent to make health care in Canada universally available and irrespective of an individual's financial situation. Similarly, the occurrence of transplant tourism by Canadians also undermines this intention, as purchasing an organ on the black market is not an option all Canadians have available to them. For example, the price of a transplant tourism package that includes a kidney purchased from a trafficker and a transplant operation in a Global South country could be as high as \$200,000 (Shelley, 2010, p. 74)¹. The question then is what is happening in the Canadian system that participating in an illegal and risky organ trafficking market in another country becomes not only a viable, but attractive, option for patients with organ failure? This question has stimulated my interest in studying OTDT systems in Canada and further directed me to explore the strategies employed in Ontario through TGLN. The chosen approach for exploring TGLN is institutional ethnography (IE), a sociological method of inquiry that maps the relations which synchronize the activities of people working within an institution

¹It is important to note that the organ donor will typically only receive between \$3000-5000, if payment is received at all. This is not even enough to cover the bi-annual post-operation medical appointments recommended for kidney donors. Significantly, sellers are almost always unaware of the health consequences of being a donor (Scheper-Hughes, 2007, p. 4).

(Smith, 2005, p. 29). Using this methodology, I will analyze primary documents created by TGLN to further our collective understanding of how TGLN processes organize activities related to OTDT in Ontario.

II. LITERATURE REVIEW

The following literature review is divided into five sections. The first deals with the concept of repugnance to certain kinds of transactions and emphasis on the efficiencies of market-based solutions. The second discusses autonomy of the body and the individual right to sell one's own organs for financial gain. The third section addresses the moral argument proposed by some scholars, which asserts that a market for commodified organs is a win-win solution for the seller who is rescued from their poverty and the buyer who is restored with health and vitality. In the fourth segment, the intersection of privilege and poverty is examined against the backdrop of organ trafficking. Finally, the fifth section will explore Canadian responses to transplant tourism and the organ crisis with a focus on the province of Ontario.

Repugnance and the Efficiency of the Market

Respected economist and Nobel laureate Roth (2007) is frustrated by repugnance. Repugnance, revulsion, disgust, abhorrence—these particular emotions can be the source of unfounded objections to the sale of particular products or services. Roth explains that when working alongside fellow economists in the design of markets and allocation procedures, they “have often found that distaste for certain kinds of transactions can be a real constraint on

markets” (p. 38). In 2007, Roth made a case for this theory of repugnance in the *Journal of Economic Perspectives*. His unmasked intention was to encourage economists to “understand better and engage more with the phenomenon of repugnant transactions” (p. 38). Reflecting on markets that have experienced this repugnance factor, Roth convincingly dissects the seemingly senseless law against horse meat for human consumption in California. He explains that this law is not intended to protect consumers from a danger associated with consuming horse meat, nor is it written with intention to protect the horses from slaughter. The apparent sole reason for the law is that voters found it repugnant for humans to consume horse meat (it appears to still be suitable for dog food, however) (Roth, 2007, p. 37-38).

In other markets, such as indentured servitude and slavery, repugnance has resulted in illegality (p. 39).² Roth also reflects on the overcoming of repugnance to markets such as life insurance and labour,³ both of which are now ubiquitous (p. 49). He uses these examples to demonstrate the folly of repugnance to the sale of human organs and tissue, concluding that to be guided by an intuitive feeling of aversion is without merit. Satz (2010) offers another ‘common-sense’ argument for legalizing a market for organs: society wishes to increase their supply (p. 189). It makes sense, explains Satz, to cite repugnance as a reason to ban the sale of things society wishes to cease or at least decrease the availability of, such as prostitution, child pornography or illicit drugs. However in the case of organs, “we have an interest in motivating

²Roth seems dismayed at the former’s ban, noting that servitude was once a common way for Europeans to earn room and board on ships sailing across the Atlantic Ocean to America (2007, p. 39).

³McNally (2008) details the disconcerting history of the commodification of labour, noting that “the selling of one’s labour was [once] a deeply offensive idea. This had to do with the fabric of social-economic relations in most pre-capitalist societies” (p. 46).

people to act in ways that increase the supply of transplant organs,” observes Satz (p. 189).

Therefore, these individuals argue that prohibiting the sale of human organs seems to make little economic sense.

Autonomy of the Body: The Right to Sell Yourself

Relieving the chronic organ shortage by increasing the supply of transplant organs through a commodified system would be a primary gain from trade. But for the libertarian, there is an equally important reason to permit such a system: prohibiting the sale of organs by owner—that is, preventing an individual from selling their own kidney—is an offence to autonomy of the body. It could be said that libertarians feel a certain repugnance to anything that infringes on personal liberty, and as such, they insist that the commercialization of organs by owner is “merely a way of recognizing their legitimate sphere of control” (Satz, 2010, p. 189). Cherry (2009) advocates for the freedom to sell one’s own organs, purporting it is but an extension of the moral authority of a person over themselves (p. 651). Cherry argues that “paternalistic public policy seeks to protect persons from themselves, to counter their thoughtfully considered and reasonable free choices from which they expect to benefit” (p. 652).

Wilkinson (2011) explains that the belief in personal sovereignty is “often expressed in terms of a private sphere with absolute powers of decision.” Wilkinson draws the hard line, maintaining that the freedom to make decisions about one’s own body is of greater importance than the threat of “catastrophic” results from these choices (p. 20). Socialist activist McNally (2008) is of another opinion: “What is deeply disturbing about this trade,” he writes, “is that

human identities are inextricably bound up with our bodies” (p. 41). He cites German philosopher Immanuel Kant who rejects the ‘person as property’ argument, contending that “man cannot dispose over himself” (as cited in McNally, 2008, p. 42).

Hegel, another German philosopher, extends this argument, declaring that the body cannot be separated from personhood and thus should not be regarded as an object: “My body is the embodiment of my freedom. Because I am alive as a free entity in my body, [my body] ought not to be misused by being made a beast of burden” (Hegel qt. in McNally, 2008, p. 42). Hegel’s argument for bodily freedom is distinctly different from the freedom argument supported by libertarians. Applied to the organ trade debate, the libertarian view contends that prohibiting persons from selling parts of their body conflicts with individual freedom, while Hegel’s perspective would suggest that those who *take* organs are exploiting the seller, and thus restricting his freedom. So while the personal sovereignty argument may appear to justify the selling of one’s own organs as a mere extension of freedom, the possibility remains that the financial situation which would make selling one’s own organs irresistible is much closer to entrapment than freedom. This is especially relevant within the current debate where, increasingly, organs sales are advocated as being not only the best option for the poor, but potentially the only option.

The Morality of the Market

Libertarian philosopher and bioethicist Taylor (2005) is another advocate for the morality of markets.⁴ Taylor is certain of the inexpensive and practical simplicity of implementing a legal organ market. Furthermore, he is highly convinced of its morality. The “simple solution” of legalizing the sale of human organs would not only save the lives of patients with organ failure, but alleviate the “abuse and suffering of yet thousands more people who, although not in need of transplant organs, live in poverty” (Taylor, 2005, p 1). Like Roth, he identifies the main opponent to organ markets as the repugnance factor, saying “to many persons markets have a whiff of sulphur about them” (p. 1). He makes a case for distaste as the greatest opposition to organ sales—“most simply,” Taylor contends, “that such markets are viscerally repugnant” (p. 3). He further laments that markets are so often described in extremes: accounts of the starving poor and the gluttonous rich that fabricate and fuel a concerning “us” versus “them” dichotomy (p. 2).

An individual trying desperately to save her own life is not fairly characterized as greedy, and further it is certainly possible that there would be many examples of transactions in a legal market for organs that are beneficial to both donor and recipient parties. It is largely for this reason that Taylor considers the legalization of organ sales a moral imperative (p. 3). In response to the claim that allowing organ markets would discourage other methods of organ procurement, he highlights that even if this is true, the result is still more available transplant organs. “To

⁴ Taylor is also the author of the upcoming book *Toxic Trade? An Unapologetic Defense of Universal Commodification*, which is significant to the final discussion of this paper on universal commodification.

advocate the legalization of markets in human organs is thus an *inclusive* approach to organ procurement rather than an *exclusive* one,” explains Taylor, “for such markets could operate alongside other approaches to procuring transplant organs” (p. 3) He admits that alternative, non-market means of obtaining organs, such as voluntary donation, would almost certainly decrease, but assures that the additional number of transplant organs obtain through a bodies market would exceed the decrease felt in other methods of acquisition (p. 3).

Scheper-Hughes (2007) identifies and reflects on the growing trend where neo-classical global economists and bioethicists “now argue that free markets, including body markets, are liberating in their valuing of individual choice, autonomy and the impersonality of the economic exchanges” (p. 3). Davis and Crowe (2009) point to the ethical concerns of monetizing organ donations, noting that “organ transplantation entails the inherent risk that one human being, a donor, will become little more than a means to the end of healing for another human being and that he or she will come to have a purely instrumental value” (p. 596). Scheper-Hughes, Davis and Crowe, and Jha and Chugh continue to oppose market-based solutions to the organ shortage, insisting that financial incentives for donation will disproportionately attract the poor and vulnerable as donors (Scheper-Hughes, 2001, 2003, 2005, 2007; Davis and Crowe, 2009; Jha and Chugh, 2006; Matas and Kilgour, 2007).

Epstein (2006) counters this position by arguing that small market-based transplantation systems should be allowed for experimental purposes in order to determine if this fear is founded. However Scheper-Hughes (2007) argues the black market for organs is already a testing ground, and it has demonstrated that commerce in organs works to amplify the dichotomy

between the rich and the poor (p. 3). Breaking down the patterns observable in the trafficking of organs reveals the system's disturbing pattern of dictating who is worthy and who is unworthy of organs, based on intersections of privilege or oppression. This is not unlike other varieties of human trafficking. I remain personally unconvinced that this trend of exploitation would not replicate itself in a legal market for organs. Furthermore, as Moniruzzaman (2012) argues permitting the sale of organs is not only devastatingly exploitative and ethically unjustifiable, but represents a new form of "bioviolence" against the poor who are only further marginalized by the exchange of money for their body parts (p 70).

Jha and Chugh (2006) make a significant observation that advocates of a legal market for organs tend to allocate their compassion to patients lingering on wait lists with end-stage organ failure ahead of those who are in such desperate need that they become sellers of their own organs. They also postulate that once the pool for domestic donors who are motivated by money (understood by the authors as also disadvantaged) is exhausted, a globalization of this "bodies market" is the inevitable next step, and large swarms of donors will come from the "developing world" to provide organs to the "industrialized world" (p. 466). Jha and Chugh insist that permitting organ sales anywhere in the world would "open the doors for rampant exploitation of the underprivileged in areas that are already plagued by vast economic inequalities" (p. 467). Moniruzzaman (2012) adds that the liberal bioethicists who support decriminalizing organ sales are, perhaps unknowingly, fostering a "symbolic violence" by focusing disproportionately on the value of the lives of patients in need of organs. When the emphasis is on the "need" for organs

and improving transplant success, bioviolence against the destitute sellers of kidneys—whose lives apparently hold less importance—is dangerously overlooked (p. 86).

Privilege, Poverty and Moral Imperatives

Just as it is both plainly inaccurate to categorize patients seeking a life-saving organ as “greedy,” it is also fallacious to suppose that the removal of patient intent to exploit an organ seller thus obviates exploitation. There is a power-dynamic at play between those who are in need of a new organ—and, quite significantly, can also afford to pay for one—and those who are so financially destitute that auctioning off of their organs becomes the best chance at survival. Acknowledging the role of privilege in both legal and illegal markets for organs is crucial to understanding the power-dynamics embedded in the trade.

“Privilege” is not a word often used in the discussion of organ markets by economists. A. Bailey (1998) has an explanation for this, noting that “one of the functions of privilege is to structure the world so that the mechanisms of privilege are invisible—in the sense that they are unexamined—to those who benefit from them” (p. 112). Persons with extreme privilege, such as myself, do not *intend* to enjoy advantages at the disadvantage of others. However, regardless of intention, I do enjoy such advantages and the organ trade creates a new dimension of this type of invisible privilege. Jha and Chugh (2006) caution that domestic markets for organs will give way to a global one, deepening agents of privilege and oppression and contributing to a culture that sees the poor as simply a means to an end, which is the existing environment in black market organ sales (p. 466).

Another crucial downfall of proposals to legalize organ markets is that poor people need organs too. The financially and socially disadvantaged are just as susceptible to organ failure as anyone else, but if we allow for a market where organs are allocated based on ability to pay, increasing class disparity will most likely follow. Satz argues that “no one’s ability to participate in their society should be blocked because they have too little money, or are too uneducated” (as cited in Goldman, 2008). Some have suggested instead of the recipient paying for the organ, the state or another public body would purchase the organs and then distribute them based on need (Richards, 2012, p. 83). That way, those who cannot afford organs could still acquire them, all the while financially supporting the donor. Yet this presents a conflict of interest: incentives for the state to provide welfare for the poor would be diminished, and the sale of organs would begin to appear as an attractive and even sensible “solution” to poverty. Indeed, even some former passionate detractors of a commodified organ network, such as Veatch (2003), now claim that “the time has come [for opposers of organ markets] to admit defeat” (p. 32). Society has turned its back on the poor, he concedes, tolerating crippling poverty amidst opulent wealth; and so to declare it unlawful to sell the one valuable commodity Veatch says the poor have—their organs—is inexcusable. “If we are a society that deliberately and systematically turns its back on the poor,” Veatch continues, “we must confess our indifference to the poor and lift the prohibition on the one means they have to address their problems themselves” (p. 32). These kinds of arguments perceive organ markets as the only solution to poverty in an unshakeably unjust world.

Richards (2012) accepts that the world is unfair. She also is convinced of its inevitability, and argues that society cannot act solely on concern for fairness. Transplantation itself is an extremely exclusive club, open only to members of the richest countries, but if one is going to use this argument to object to the relatively rich participating in a market for organs, Richards contends that one should also admonish all other disparities in access to health care (p. 82). This argument may make sense to an audience outside of Canada, but within it, this is precisely the mandate of the country's health care system: "universal coverage for medically necessary health care services provided on the basis of need, rather than the ability to pay" (Health Canada, "Health Care System"). Canadian patients who engage in transplant tourism are therefore "jumping the line" and using their relative wealth to avoid the wait list, which is problematic for the Medicare system established in Canada. The objective of Canada's universal health care policy is to operate on specific principles of equality. Making an exception for organ and tissue transplantation by letting it descend into the marketplace impedes the foundation upon which Medicare was first established (Health Canada, "Health Care System").

Canadian Responses to Transplant Tourism and the Organ Crisis

Transplant tourism places Canadian doctors and other medical professionals in the difficult position of caring for patients who have engaged in transplant tourism upon their return. Prasad, Shukla, Huang, Honey, and Zaltzman (2006) conducted a study regarding Canadian cases of transplant tourism and found that emergent medical care was necessary for 52 percent of the patients returning to Canada after having illegal transplant surgery abroad, while hospital

admission was required for another 33 percent (p. 1131). G. I. Cohen (2013) outlines some of the complications that contribute to this, including lengthy travel too soon after surgery and incomplete medical documentation, some of which is in foreign languages (p. 273).

Though secrecy around the practice have made exact figures impossible to obtain, the prevalence of Canadian patients who engage in transplant tourism is so concerning that in 2010, the Canadian Society of Transplantation (CST) and the Canadian Society of Nephrology (CSN) produced an official policy statement on organ trafficking and transplant tourism. The intended audience of the policy statement is healthcare professionals involved with patients who have end-stage organ failure (Gill, J.S., et al., 2010, p. 817). It is made clear that physicians have a responsibility to care for patients in emergent need, even ones who have participated in transplant tourism or other illegal forms of acquiring organs (p. 819). However, the CST and CSN have also directed physicians to dissuade patients who may be thinking about travelling abroad to purchase an organ. For example, they are not to prescribe or otherwise assist in the obtainment of medication used in the process of transplantation and are encouraged to exercise caution in the release of medical records relevant to pretransplant assessment. In addition, individual physicians may refuse to release medical records to patients they feel convinced intend to use the information to facilitate an illegal transplant operation (p. 819). Thus, efforts, such as the ones outlined by the CST and CSN, have been undertaken to attempt to stem the problem by specifically engaging with the phenomenon of transplant tourism (Wright et al., 2013, p. 923).

The ten provinces and three territories of Canada have each had their own response to address the organ crisis, particularly through working to increase the rate of donation. Medicare, Canada's nation-wide health care system, is aptly described as an interlocking system of insurance plans as applied by individual provinces and territories. While they share the same fundamental features and standards of coverage as established by the *Canada Health Act* (CHA), the provincial-territorial governments within Canada are responsible for implementing and regulating systems such as OTDT (Health Canada, "Canada's Health Care System (Medicare)").

Within Ontario, this has manifested in the creation of Trillium Gift of Life Network (TGLN). Created following the *Trillium Gift of Life Network Act* in 2002, TGLN is a not-for-profit organization of the Government of Ontario. It is exclusively in charge of the planning, promotion, and coordination of OTDT throughout the province (TGLN, "What is Trillium Gift of Life Network?"). Donation rates in Canada have been both abysmally low and failing to improve, and this was especially true in the province of Ontario, which has historically had some of the lowest rates of donation in the country (*Call to Action*, 2011, p. 10). In 2010, studies demonstrated that while 90 percent of Ontario residents were in favour of organ and tissue donation, only 17 percent were registered as donors (Hill, 2010). Former president and chief executive officer of TGLN Frank Markel spoke on these figures, lamenting that "the tragedy is all these people's lives can be saved if we had enough donors. And we don't have enough donors in Ontario" (as cited in Hill, 2010). In response to this crisis of low registration and rate of donation, in 2012, TGLN produced a three-year strategic plan to buttress the planning,

promoting, coordinating and support of OTDT in Ontario (TGLN, “TGLN 3-year Strategic Priorities”).

Three primary priorities have been identified as a part of this three-year plan to be achieved by March 31, 2015. The first set of priorities focus on sustainability and the attainment of an end-to-end transplant system while striving to “improve the dimensions of quality, safety, effectiveness, access, patient centred and integrated care” (TGLN, “TGLN 3-year Strategic Priorities”). The second priority is to significantly increase the rate of organ and tissue donation, with a focus on Greater Toronto Area hospitals. The third and final priority hones in on increasing the number of registered donors, again with a focus on the Greater Toronto Area. Specifically, TGLN is looking to reach one million registered donors by March 31, 2015; an increase of 89 percent from 2012 (TGLN, “TGLN 3-year Strategic Priorities”).

The 2011 strategic plan *Call to Action* was developed by Canadian OTDT communities in collaboration with Canadian Blood Services to provide an exhaustive list of challenges and opportunities in the OTDT environment. The information contained in this document likely contributed to the development of TGLN’s three-year strategic plan, which was released the following year. The objectives identified in *Call to Action* are to reduce waitlist times for patients anticipating a transplant, bolster the domestic production of tissue products, and help diminish transplant tourism (*Call to Action*, 2011, p. 4). Canadian OTDT communities are expressly aware of the affect low rates of organ donation, and shortcomings in organ allocation processes, have on incidence of transplant tourism. They recognize that Canada has been complicit in allowing

transplant tourism and other forms of organ trafficking to flourish, and accordingly efforts to improve the Canadian OTDT system are expected to mitigate this phenomenon.

III. METHODS

Theoretical Approach

As discussed in the literature review, the awe-inspiring advances in biomedicine and transplant surgery have spurred new questions about the divisible body and its potential for commodification (Scheper-Hughes, 2007, p. 3). Scheper-Hughes (2007) argues that “commercialized transplant medicine has allowed global society to be divided into two decidedly unequal populations—organ givers and organ receivers” (p. 4). Efforts to foster equilibrium in the supply and demand of transplantable organs have led many to argue for market-based solutions (Banks, 1995; Becker and Elías, 2007; Cohen, L.R., 1989, 2001; Cherry, 2009; Epstein, 2006; Novelli et al, 2007). What is made invisible in these discussions of market-based solution is the operation of power and privilege in contemporary society.

Acknowledging the role of privilege in both legal and illegal markets for organs is a fundamental assumption reflected in my research approach. To a disadvantaged organ donor, an organ trafficker may be perceived as a criminal who deceived and cheated them. To the advantaged organ recipient, however, an organ trafficker can be perceived as someone who worked outside a flawed legal system to save their life. These disparate perceptions are socially-constructed through systems of oppression and the invisibility of privilege. The organ trade has created a new dimension for the deserving and the undeserving. It is essential to address the

influence of invisible privilege on commercialized strategies for mitigating transplant tourism and improving legal systems of OTDT.

It is similarly crucial that I examine my own place of privilege as a white, Canadian, able-bodied, university student researcher examining the topic of OTDT. Pease (2010) reflects that “there has been an explosion of social science literature dealing with the experiences of discrimination” (p. 4), which extends to the oppression of marginalized populations. Strategies are developed to demonstrate to the oppressed *their oppression*, making the assumption that liberation is up to *them* and that *they* must be the ones to challenge dominant discourses and the hegemonic classes. Pease takes issue with this approach challenging those in positions of privilege to think about the ethics of putting the burden of responsibility solely on the oppressed while those who benefit from these structures of oppression remain largely unaware and often unconcerned with the role we play in perpetuating inequality (p. 5).

Pease (2010) also references world systems theory, which postulates that the most “developed” nations, the ones that control the majority of capital flows worldwide, have attained this place of supremacy historically through conquests, colonialism, trade policies slanted in their favour, and financial buttressing from The State (i.e., various formal government bodies). Meanwhile, explains Pease, “less developed nations are caught in a dependency relationship with developed countries through foreign debt, import and export patterns and the practices of multinational corporations” (p. 40). This theory of a global hierarchy is consistent with trends of international organ trafficking, where Global North inhabitants exploit the bodies and body parts of Global South citizens and feel justified in doing so because their own intersections with privilege are invisible.

Canada prides itself on being an egalitarian society, and, as Pease points out, such societies are typically more responsive to global human rights offences. People travel to help ‘fix’ the problems in other countries. However, I would argue that in so doing they may unwittingly perpetuate transplant tourism their personal lack of reflexivity in terms of the role that Canada plays in globalized markets of organ trade. Thus, even in their advocacy work, these individuals remain unaware of their role in creating and sustaining inequalities (Pease, p. 61). It could be postulated that though many human rights advocates from Global North countries travel to Global South countries to fight oppression, it may actually be more appropriate to address the privilege that has created and sustained this oppression instead. Sometimes this means staying home.

One of the ways in which researchers have explored organ trafficking rings is by “studying-down,” or investigating the realities of marginalized communities. For example, L.R. Cohen (1989, 2001, 2005) has written extensively about organ trafficking and organ donation and transplantation programs, advocating on the side of market-based solutions. L.R. Cohen (2001) has also conducted an ethnography of kidney or renal transplantation practices in India through “extensive clinic visits and talks with nephrologists, urologists, state regulators, kidney sellers and brokers of organs, information and ethics” (p. 9). Another example is Scheper-Hughes (2004), who has, among her many organ trafficking research endeavours, published an undercover ethnography of the subterranean black market for organs. While these sorts of studies are undoubtedly valuable in informing an understanding of the organ trade at large, they still fall into the category elucidated by Pease (2010) of “studying down” (pp. 5-6).

Previous scholarly explorations of my own into organ trafficking have examined concerns in Turkey, China, India and Brazil. Rather than studying foreign countries, my current study of transplantation systems in Canada appears to have two key advantages: (1) informing a gap in my own, and others', knowledge about how Canadian systems of OTDT have reinforced a culture where transplant tourism becomes a legitimate option for patients; and (2) addressing aspects of the systems that have relative power and privilege instead of focusing on marginalized groups as an attempt to engage in research that is both underdeveloped and significant to understanding the demand side of organ trafficking.

The following section outlines how I will use institutional ethnography (IE), a sociological method of inquiry, to address the research problem outlined above. IE diverts from traditional sociology, in which people are objects whose behaviour is to be rationalized, and instead examines the social relations that govern everyday experiences (Smith, 2005, p.1). I am adopting DeVault and McCoy's (2006) interpretation of IE "to refer to the investigation of empirical linkages among local settings of everyday life, organizations, and translocal processes of administration and governance" (p. 15). As Smith (2006) further elucidates, IE "goes from where actual people are in their own lives, activities, and experiences to open up relations and organizations that are, in a sense, actually *present* in them but are not observable" (p. 3; emphasis in original). The ways in which these "social relations" can be studied are vast and varied. This specific study will look at how texts play a role in organizing the actions of individuals within a larger system.

Research Design

A key assumption I have going into this research project is that Canada's OTDT system is unnecessarily failing patients. I also maintain that a solution to the challenge of successfully procuring and distributing organs can be attained by going beyond the imaginations of neoliberal economists and bioethicists who contend that since organs are already being sold on the black market, legalizing their sale is the only way forward. My research approach is founded on a commitment to address Canada's complicity in the trafficking of organs, and specifically transplant tourism. I posit that an institutional ethnography exploring the texts, forms and documents employed by members of Canada's OTDT community will prove valuable in illuminating the inner-workings of this unique aspect of the medical community. I reason that this type of investigation can inform broader understandings of the challenges and opportunities to foster a more successful system in Canada. Recognizing the significance and function of text in this field is the central aim of my research.

IE is an appropriate method of inquiry for my interest in promoting alternatives to an organs market and the commodification of bodies through the organ trade. The value of an IE-informed approach when doing a discourse analysis is that it recognizes the central role of texts in institutional processes and to: "reach beyond the locally observable and discoverable into the translocal social relations and organization that permeate and control the local" (Smith, 2006, p. 65). Examining the connection between specific texts and the larger relations of power within which these texts operate will serve to provide an in-depth understanding of the OTDT process in Ontario, giving the researcher an opportunity to identify what works about the process and question what is problematic in order to make way for change.

Data Sources, Parameters, and Collection Techniques

My specific interest in Trillium Gift of Life Network (TGLN) developed out of my Social Justice and Community Engagement Master's program. The program requires 120 hours of community placement, which I spent at a mid-sized hospital in Southern Ontario. I began my placement in February of 2014 and my primary responsibility at the hospital involved explaining procedural changes related to OTDT to nurses should a patient aged 79 or younger die in the hospital during one of their shifts. TGLN has devised a new strategy to attempt to increase the number of donors in Ontario and develop a more successful infrastructure within hospitals to facilitate the processes involved in organ donation, procurement and transplantation. For healthcare professionals in a hospital setting, a key part of this process is managing patient death.

It should be noted that there are two kinds of death in which patients are considered suitable for potential organ donation in Ontario. The TGLN "Donation Resource Manual" (2010) explains the more commonly-used indicator is known as neurological determination of death (NDD), involving a patient who has been declared dead based on established brain death criteria (p. 9). The other option is more complex, as the death-indicator is less clear. Donation after cardiac death (DCD) indicates a patient with a non-recoverable injury who does not meet the criteria for neurological death and is on life sustaining therapy (p. 10). Cases of DCD require more planning, and consent to donate must be achieved before the pronouncement of death (DCD potential) and withdrawal of life sustaining therapy (WLS) must also be pre-arranged (p. 15). This paper does not seek to explore the complexities of NDD and DCD death, but rather acknowledges their influence on the way patients become eligible for potential organ donation.

For the purposes of this project, I will undertake a discourse analysis of key texts in the TGLN process. The texts that I have selected were chosen as a result of my experiences during the placement described above and my observation that these forms played a vital role in the managing of TGLN procedural changes. Impressions gathered from placement observations and informal discussions, as well as the formal presentations made to groups of nurses detailing the legislated changes have led me to select the following texts for investigation (see Appendix): 1) *Routine Notification for Designated Hospitals* (2 pages), 2) *Routine Notification Worksheet* (2 pages), 3) *Next Steps Worksheet* (2 pages), 4) *Frequently Asked Questions for Healthcare Professionals* (4 pages). These constitute the primary texts healthcare professionals at hospitals across the province engage with regularly to fulfil their duties as they relate to OTDT. These documents are publicly-available on TGLN's website (www.giftoflife.on.ca) and all together constitute ten pages of text that I will analyze in-depth.

The methodology of IE will allow me to interpret these texts as illuminators of the larger structures of ruling relations. It is important to understand texts as more than just data. As Smith (2006) explains, texts *are* what people in institutions *do* (p. 65; emphasis in original). The word “institution” is not used here to refer to a single hospital, but rather as DeVault and McCoy (2006) clarify, the use of the word institution “is meant to inform a project of empirical inquiry, directing the researcher’s attention to coordinated and intersecting work processes taking place in multiple sites” (p. 17). Texts are actors which operate as coordinators of the individual activities within institutions (Smith, 2006, p. 65). The texts I have selected are not idle; they are the direct influencers of action. In IE, explains Smith, text is “recognized as a local occurrence articulated to and articulating people’s doings” (p. 67).

The intention of an in-depth discourse analysis of these worksheets, brochures and other documents is to inform my understanding of TGLN's approach to improving Ontario's OTDT system. This will involve investigating "traces of how the substance of the text as assembled, that is, where it came from, how it was put together, and how it projects organization into what follows" (Smith, 2006, p. 72). This method of rigorous analysis of key texts is significant to ascertaining both areas of effectiveness and areas that would benefit from re-evaluation in TGLN's strategy. This, in turn, could improve the system, thus improving the lives of Canadian patients on wait lists while simultaneously reducing participation in transplant tourism.

Qualitative Reliability and Validity

In order to ensure a rigorous analysis, I have used triangulation, a validation strategy which utilizes multiple and contrasting data sources, theories, and methods in order to authenticate the conclusions drawn by the researcher (Creswell, 2012, p. 251). I am inspired by the evolution of triangulation into crystallization, as advanced by Richardson (cited in Creswell, 2012). He suggests a postmodern take on the concept of triangulation, inspired by a metaphorical image of a crystal (p. 249):

I propose that the central imaginary for "validation" for postmodern texts is not the triangle—a rigid, fixed, and two-dimensional object. Rather the central imaginary is the crystal, which combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities, and angles of approach... What we see depends on our angle of response—not triangulation but rather crystallization.

This evolution of triangulation into crystallization appears to be congruent with the goals of institutional ethnography. As Smith (2005) explains, IE is “a method of inquiry into the social that proposes to enlarge the scope of what becomes visible from that site, mapping the relations that connect one local site to others” (p. 29). Richardson (as cited in Creswell, 2012) contends that what is observed is dependent on the “angle of response” (p. 249), and in IE, new observations are made as the researcher works to ‘take the standpoint’ of the persons whose daily lived experience indicates the starting point of exploration (DeVault and McCoy, 2006, p. 20).

Data Analysis and Interpretation

Discourse analysis describes an approach that understands language as exponentially more than a reflection of the world; it is instead central to the construction of social processes, ideas, and other phenomena that compose our social milieu (Nikander, 2008, p. 413). Godderis (2011) notes that discourse analysis also makes the assumption that language has productive and performative characteristics (p. 489). This paper explores the details that make up TGLN’s primary texts and organizes them into broad themes, and connects these themes to larger social repertoires to show their importance with respect to ruling relations (Godderis, 2011, p. 489). My data analysis and interpretation will seek to describe, classify, and interpret data into themes or codes. This process of looking for themes and coding will involve a comprehensive discourse analysis of the text from each document which is then divided into subsets of information, checking for confirmation of the perceived theme or code in other documents, and then giving a label to that theme or code (Creswell, 2012, p. 184).

My intention with coding will not be to make generalizations, “but to find and describe social processes that have generalizing effects” (DeVault and McCoy, 2006, p. 18). Given this objective, the need for a quantitative data set comprised of the entirety of TGLN literature is replaced with an understanding that while the four texts I have selected do not speak for the complete cannon, they bear significant relevancy in their ability to illuminate the broader organizational structure of TGLN. These texts each offer a specific perspective on the functioning of TGLN and provide information on the same generalizing set of relations which can be expected to exist beyond their specificity (DeVault and McCoy, p. 19). Again, this is not to suggest that TGLN’s texts are homogenous, but to explore the ruling relations that can be theorized to operate across the literature produced by TGLN.

Ethical Considerations

As I am not working with human participants, there are significantly reduced ethical considerations. The texts that I am using are blank, publicly-available documents located on TGLN’s website. During my placement at the hospital I observed that these forms were the most central to daily work. Analysis includes similarly general observations and reflections made during the placement in the hospital, however, these remain focused on the researcher’s personal reflections and in no way involve collecting primary data from others.

IV. RESULTS

The following is a detailed examination into the four TGLN texts most commonly used or referred to by healthcare professionals at Ontario hospitals in regard to organ and tissue

donation. These documents were obtained through visiting TGLN's official website, www.giftoflife.on.ca, and the goal of the ensuing analysis is to investigate the language employed by TGLN in discussing OTDT in these texts.

Routine Notification for Designated Hospitals

The *Routine Notification for Designated Hospitals* document is a brochure-style information packet with concise answers to frequently asked questions. It is intended to be a tool for healthcare professionals with basic questions about the new procedure for handling deaths at the hospital in relation to potential organ or tissue donors. On the front are three icons: the first, a red circle with the speaking end of a telephone depicted on it which has the word "Call" underneath it; the second, an inverted yellow triangle with a magnifying glass above the word "Screen"; and the third, a green square with a side portrait of a person with a phone headset on above the word "Connect." These "Call, Screen, Connect" symbols appear frequently on TGLN literature intended for use by healthcare professionals as quick reminder to first call TGLN to be put in touch with one of their representatives after the death of a patient (aged 79 and younger), then work with the representative to screen for ineligibility, and finally to "connect" the representative with the patients' family.

This brochure, as well as all of the other TGLN documents I am examining, continuously refers to the system of determining the potential to donate as "eligibility." However, I will be referring to this process as determining "(in)eligibility" because, as I argue below, this language more accurately reflects the objective of the screening process. This process is clearly and explicitly designed to uncover reasons why the patient *cannot* donate organs and/or tissue as

quickly as possible. The sooner the nurse finds a “no,” the sooner they can retire the TGLN form and return to standard procedure for patient death, getting them back to their other work more quickly. Thus, it seems that focusing on the process of elimination (rather than eligibility) is more efficient and therefore likely leads to cost savings. Moreover, it is possible that the strategy behind TGLN’s insistence on the utilization of the word “eligibility” versus “ineligibility” is to draw attention to a positive rather than a negative. In other words, TGLN wants to emphasize that the process is about looking *for organs*, while in reality there seems to be a stronger focus on looking *for characteristics indicating a patient’s unsuitability to donate*. It is logical to assume TGLN is aware of the potential impact of word choices, and makes their selections carefully so as to be consistent in presenting donation as a wholly positive process.

In addition to this information, the questions drafted by TGLN to address common concerns in the *Routine Notification for Designated Hospitals* brochure are worded to sound like the skeptical and apprehensive voices of the nurses who will be asked to carry out the new responsibilities associated with TGLN’s three-year plan. The end of the first question concludes with “What is this about?” contributing to the conversation-style format of these question and answer blurbs.

Question one involves legislation, specifically the *Trillium Gift of Life Network Act*, which requires designated hospitals in Ontario to comply with the “79-and-under strategy or “referral provisions,” as they are more formally called. One of the effects (whether intended or unintended) of the way the question is worded is to remind the nurses that this new procedure is law, which is emphasized in the first paragraph of the answer. The second paragraph in this answer refers to the importance of contacting TGLN after patient death so that they may consult

the Ontario Health Insurance Plan (OHIP) database, which contains information regarding individual consent to donation. This is the first step TGLN takes in determining (in)eligibility. This database informs TGLN employees if the deceased patient has officially declared their wish to be a donor, but regardless of the findings the answer makes clear that it is TGLN who will be approaching families about donation. The position of TGLN as the primary gatekeeper of the donation process, and thus the point of contact with the families of potential donors, comes up again and again in the documents and will be examined in more depth in the discussion. The answer to this question also introduces the concept of donation as an “opportunity” for families, a characterization that is frequently reiterated throughout TGLN’s literature.

The second question is: “What are the referral indicators for high risk of imminent death?” Part one of the answer, which applies to all ventilated patients, is an acronym for GIFT: “Grave prognosis or GCS (Glasgow Coma Scale [a neurological scale which records consciousness]) = 3 (ostensibly the determined number which indicates high risk of imminent death); Injured brain or non-recoverable injury/illness; Family initiated discussion of donation or withdrawal of life sustaining therapy; Therapy limited, de-escalation of treatment, or withdrawal of life sustain therapy discussion planned.” If these referral indicators are met, nurses may contact TGLN in advance of patient death and begin completion of some of the associated forms. The brochure provides different referral indicators for all non-ventilated patients, but does not provide an acronym.

Questions three and four assure the legality of providing patient information to TGLN and TGLN obtaining consent to donate from the patient’s family over the telephone, respectively. Seemingly to counteract any hesitation on the part of nurses in giving out sensitive patient

information over the phone, the *Trillium Gift of Life Network Act* is mentioned at the beginning of each answer, emphasizing that the new hospital procedures are in fact legislated by the government of Ontario and must be adhered to. Question five explores a question concerning the relationship between donation and grief of the surviving family. The brochure notes “studies” (which remain uncited and unspecified) which have “repeatedly shown” the gratitude of donor patient families. The answer paints a homogeneous picture of families who find donation to be “something positive in an otherwise negative life situation” and a means of honouring the deceased while providing the gift of life (or sight, or healing through, for example, skin transplants) to someone in need. The complexities of deciding to donate and/or any opposition that families might raise, for example for religious reasons, remain unacknowledged in this answer. Rather, positive responses to donation are emphasized in a blue box of text that follows the answer with a quote from Eya Donald-Greenland, a “proud donor family member,” who recalls the gift of sight given by her late husband. TGLN is specifically named in the quote to highlight the connection between the donation and TGLN.

Question six asks how long the notification process (Call-Screen-Connect) will take. The answer notes that the process for patients deemed ineligible is between two and three minutes, while calls regarding eligible patients may take between eight and ten minutes. The “may” is underlined and italicized in the case of eligible patients, and later in the answer bolded text is used to emphasize the words “reduce the time,” further highlighting the point that “this won’t take long.” The answer in this section of the *Routine Notification for Designated Hospitals* brochure explains that TGLN has developed worksheets that are time-saving tools for healthcare professionals. These worksheets will be examined in more detail later in this section, but what is

clear from this question (among others) is that timing of the process and efficiency is one of the central concerns of TGLN.

Next, in question seven, the Call-Screen-Connect process is explained over six steps. Step one establishes that the TGLN *Routine Notification Worksheet* is to be “prepared,” which refers to filling out basic patient information prior to calling TGLN. Once a TGLN representative is on the phone (“CALL”), they will go over a list with the healthcare professional to determine (in)eligibility (“SCREEN”). Each type of potential donation needs to be screened for separately because organs and tissue each have different protocols. If the patient is eligible to donate organs, the brochure explains in italics that the TGLN phone operator, or coordinator, will devise a plan of action with the “healthcare team for continued evaluation and support.” Based on my practicum experience at the hospital teaching about the TGLN process, I know that for organ donation the phrase “continued level of support” means that a TGLN representative will come to the hospital as soon as possible to facilitate the non-medical processes around transplantation.

It is common that a patient who is deemed ineligible for organ donation can still be a potential tissue donor in which case a representative does not visit the hospital but continues coordination over the phone. This, I was told during my placement, is due to the high frequency of individuals who choose to donate tissue, which involves a relatively non-invasive technique. The following steps are thus provided for tissue exclusive donors, as in the case of organ donation, a TGLN representative would see to these tasks.

Step two explains that the process for tissue exclusive donors is to get the patient’s family on the phone with the TGLN Coordinator (“CONNECT”). It is advised to secure a private location with a phone. Step three instructs that the patient’s chart, as well as their body, is to

remain on the unit (if possible), while the Coordinator speaks to the family. Step four refers to the completion of the *Next Steps Worksheet*, which is to be filled out by the healthcare professional either when the family consents or in the event that the family is unavailable at the time the death is reported to TGLN. Step five involves cooperating with instructions given by the TGLN Coordinator regarding preserving the tissue for donation, an example being closing the eyelids. The final step requests that after patient-family consent to donation, a copy of the consent form (which will be faxed by TGLN) be added to the patient's chart.

In question eight, the discussion centres on the protocol for when the patient's family is not present at the hospital. Once the initial steps to determine the potential to donate are completed, TGLN will arrange to contact the family by phone while continuing to secure relevant clinical information about the patient. A form will be faxed to the hospital from TGLN headquarters indicating the need to contact TGLN before the body of the deceased patient is released to the morgue in order to "ensure the opportunity to donate is not lost."

Question nine asks why healthcare professionals are to avoid discussing donation with families. This directive seems to be of particular importance to the functioning of TGLN, as it is reiterated numerous times throughout the four texts. This trend will be further addressed in the discussion section. The answer to question nine points to unspecified research which reveals the effect an individual's comfort level and experience in discussing donation with families has on their likelihood to donate. Tissue is specified in this answer, leaving out a significant conversation about organs. The pamphlet is not clear in this instance if healthcare professionals are only to refrain from discussing donation when it is tissue exclusive, although other

documentation and my experience at the hospital indicates that a donation of any kind is only to be discussed with the family by TGLN.

The *Trillium Gift of Life Network Act* is mentioned and has the effect of legitimizing and enforcing the requirement. I would argue this is a common strategy employed by TGLN since this is the fifth time it has been named in the document. After emphasizing the legislative requirement to leave the discussion of donation to TGLN, a rationalizing argument is used. TGLN Coordinators, the brochure explains, undergo quarterly training both in person and over the phone for discussing donation with families, resulting in improved rates of positive consent as compared with approaches by hospital staff. As a caveat, the final portion of the answer makes clear that in the instance a hospital staff person discusses donation with the family and reports to TGLN that they are uninterested in donation, TGLN may contact the family regardless to ensure they have all the appropriate information before making that decision, such as a registered consent to donate by the deceased.

Question ten is a concise question and answer addressing the protocol for when families inquire about donation before being asked. In this case, family members are to be told they will be put in touch with (“CONNECT”) the “donation specialists,” TGLN, to discuss options and share information. Question 11 inquires about two things: how TGLN determines if the deceased patient is a registered donor, and how this information is then relayed to families. It is immediately noted that TGLN alone has access to the OHIP database, which includes information about consent to donation. Once what TGLN refers to here as the establishment “initial medical suitability”, only then is the information about individual consent accessed.

Only when consent to donate is registered does TGLN provide this information to family members. This seems to be important for TGLN to emphasize as a means of addressing the fear that anyone involved in the donation process may be less inclined to save a patient's life if they know they are an organ donor. This is apparently an established concern for individuals considering registering to be a donor, as indicated in the frequently asked questions section of the TGLN official website, where it is asked if "everything will be done to save my life" if they have registered as a donor (TGLN, "FAQ"). The answer to question 11 in the *Routine Notification for Designated Hospitals* brochure continues, indicating that family members are provided with support in coming to terms with a "loved one[']s" decision to donate and what the next steps are. However, instead of simply saying the decision to donate, the pamphlet says the decision to "save and transform lives." This reiterates the main point TGLN want to get across: donation saves and transforms the lives of other patients. Use of the phrase "loved one" instead of "deceased patient" is also common through the TGLN literature, possibly to strategically demonstrate TGLN's acute awareness that the donor is not just a body of spare parts for use, but a person who was loved.

Question 12 begins with a statement: "Providing clinical information to TGLN can take some time. How can this time be minimized?", the imaginary healthcare professional asks. The answer employs words like "organized" and "streamlined" to emphasize the efforts made to decrease the amount of time healthcare professionals need to remain on the phone with TGLN. Two new purposes for engaging with TGLN are then listed: in addition to organ and/or tissue donation, bodies may be eligible for research and training purposes. Question 12 asks if families are made aware if the organs or tissue of their loved one have been recovered for transplant or

research purposes. The answer is a bolded yes. When organs and/or tissue are transplanted to save or improve the life of another patient, the family receives a thank you letter from TGLN. If for some reason, transplantation does not occur after consent and determination of (in)eligibility, the donor family is contacted by a TGLN representative and thanked for their generosity. It is suggested that this may be hard for donor families to hear after having made the sometimes difficult decision to donate, TGLN takes care to explain in this *Routine Notification for Designated Hospitals* brochure that “all possible measures” were taken to attempt to recover and transplant the organs and/or tissue and “honour their gift.”

The final question concerns itself with obtaining approval from the Coroner for the donation process. The answer first assures the reader that the provincial Coroners from the Coroner’s Office of Ontario are avid supporters of donation. If a potential donation case requires Coroner permission, TGLN will contact the Coroner to establish permission.

At the end of the brochure is the TGLN “Gift of Life” logo, and two telephone numbers, one toll free and one based in Toronto, to access the TGLN provincial resource centre. These phone lines are open 24 hours a day, seven days a week. Those interested in more information are also directed to TGLN’s website, www.giftoflife.on.ca. Finally, beadonor.ca is advertised, a subsidiary TLGN website exclusively for individuals to register consent to donation in Ontario.

Routine Notification Worksheet

The *Routine Notification Worksheet* was alluded to in the previously described brochure. It is a two-page document for use by healthcare professionals (and primarily used by nurses) that begins with the name of the document followed by the TGLN tagline - Call Screen Connect- and

the two telephone numbers listed at the end of the brochure, one toll-free and one Toronto number. In a bolded “tip” box, a reminder is given to ensure this chart is out and ready for the call. Another box at the top of the document contains check-out boxes to indicate if 1) after a conversation has been conducted between the healthcare professional and a TGLN Coordinator, a patient is eligible or not eligible for donation; and 2) if a call is required at the time of death. The latter is redundant; one would only check “Yes” if the patient was eligible for donation. The intention is likely to reiterate the need for a call at the time of death. Another line within this small box is for entering the TGLN case number which is given by the Coordinator to each call that is made.

After this preliminary section, the (in)eligibility process begins. Some of the areas on this chart may be filled out in advance of patient death, such as their name, date of birth, hospital record number (MRN) and Ontario Health Number. This would occur in cases where a patient was expected to pass soon, such as in the palliative care unit. The clinical history of the patient may also be filled out before the time of death. This history is denoted by checkboxes in a column on the right-hand side. This is one of the most important areas of the *Routine Notification Worksheet* as it determines (in)eligibility. Depending on what is checked off, the patient may be unsuitable to donate organs, tissue, or both. The areas of concern are as follows: HIV, Hepatitis B, Hepatitis C, MRSA (current), VRE (current), C. Diff (current), ESBL, CJD (Mad cow), rabies, TB (Tuberculosis), Alzheimer’s, Parkinson’s, ALS (Amyotrophic Lateral Sclerosis or “Lou Gehrig’s Disease”), MS (Multiple Sclerosis), Leukemia, Lymphoma, documented Sepsis, and isolation precautions. Note that these are not placed in alphabetical order.

Below this columned-box is another one which simply states: “Note: Eligibility is assessed on a case-by-case basis.” It is unclear what is meant by this; on the one hand, it is true that (in)eligibility is determined individually for each patient via the completion of this chart, but on the other hand, the determination of (in)eligibility appears to be uniform. It appears to be a potential strategic statement that provides TGLN with a loophole to disqualify a patient, even if that individual meets all of the stated criteria. While flexible decision-making can be important, such loopholes can also have unintended consequences. Possible implications of this language, and how such flexibility may actually reinforce problematic tendencies in the system including institutionalized homophobia, will be examined further in the discussion section. For example, of the ways in which TGLN has been documented to reject donation from otherwise eligible patients is from gay or bisexual men with a history of male-to-male sexual activity.

The remainder of the first page asks for general information regarding the patient’s death, as well as entrance or admission to the hospital. There is also a section to fill out information regarding the next-of-kin (NOK) in the event that the patient is determined to be a potential tissue-exclusive donor. A reminder is included to document the communication with TGLN in the patients’ chart. Page two begins with some checks to perform if the client is “ventilated” (original emphasis). This denotes a patient who is potentially eligible for organ donation. This section of the worksheet is also simply a preview of what to expect the TGLN Coordinator to ask, beginning with the patient’s admission history. The next question is quite significant, and inquires about the presence of a brain injury (such as from a stroke, cardiac or respiratory arrest) on the admission history. Brain injured patients are ideal for organ transplants as they are hooked up to ventilation machines which push oxygen through their blood,

maintaining healthy organs for transplant. The TGLN Coordinator will ask the following regarding the neurological assessment findings: pupil response to light, cough and gag reflexes, response to pain, ventilator settings and mode, patient's respiratory efforts, and use of sedation/paralytics. The Coordinator will also ask about plans to discuss withdrawal of life sustaining therapy and de-escalation of care in anticipation of death, and finally about the presence of the patient's family and the plan of care going forward.

The end of this section concludes with two important directives, both of which serve as reminders that the final decision is securely in the hands of the TGLN Coordinator. First, it is noted that the Coordinator will inform the healthcare professional if the patient is eligible for organ and/or tissue donation. Then, in a bolded, larger typeface, it is indicated that Coordinators will, "when appropriate," request to be put on the phone with the patient's family. By communicating that the Coordinator will make the request, it appears to be in the Coordinator's hands to decide on an appropriate time to transition to speaking with the family. There is also a reminder when transferring the call to the patient's family to explicitly refer to the TGLN Coordinator only as a Coordinator who works with the hospital. The reason given is so that the family is assured that the patient's care is "coordinated." However it is also significant that TGLN not be mentioned so as not to initiate a conversation between the healthcare professional and the family about donation, an issue that I will return to in the discussion section.

Lower on the worksheet, it is noted that if a family should inquire about the subject of organ and tissue donation to the healthcare professional, TGLN can be mentioned. The family will be informed that TGLN will be "available" to discuss donation. The word "available" is worthy of attention because it implies that the Coordinator will be on hand to answer the families

questions, should they have them, not that there will absolutely be a conversation that takes place. During my placement, I learned that if the family does not inquire about donation, and the patient is deemed ineligible by TGLN, the subject of donation will not even be raised. However, if the family is inquiring about donation, and TGLN deems the patient ineligible, the family may have questions regarding the decision, and if so, the Coordinator will be available to discuss the decision and donation in general. Again, the point is that the entirety of the discussion and education regarding donation is to be handled by the TGLN Coordinator, not the healthcare professional.

The final section of this worksheet provides specific language and scripts to use when connecting the patient's family with a TGLN Coordinator. There are two given "possibilities," and healthcare professionals are encouraged to familiarize themselves with these short scripts. Possibility one is referred to as guiding family through "end-of-life." They are to respond when families ask, "What do we do now?" with "One of the next steps for families is to speak with a Coordinator to help with some of the decisions that you will be making. We can arrange that now or in a little while, before you leave the hospital." The second possibility is referred to as normalizing. Here, there is no question posed by the family, simply a script that reads, "As part of end-of-life care and to help with some of the decisions that need to be made, we arrange for families to speak with a Coordinator on the phone." The second sentence of this script is identical to the first. The language of these scripts reiterates the vagueness necessitated when referring to the "Coordinator." As explored further in the discussion section, the goal of being vague is to ensure that only TGLN approaches the subject of donation with families.

Next Steps Worksheet

The *Next Steps Worksheet* is for use when a patient has been deemed eligible for either organ or tissue donation by a TGLN Coordinator. The TGLN contact numbers are given at the top of the first page in a separate box. Also at the top is a line to enter in the TGLN file number. The worksheet really begins with explaining that the ensuing questions will be asked in order to “further assess donation potential.” The Coordinator is no longer referred to as a “TLGN Coordinator,” but “The Provincial Resource Centre Coordinator.” This Coordinator is still an employee of TGLN, however they are differentiated from the first TGLN Coordinator the healthcare professional speaks to. As for the questions, discretion is given that the coordinator will ask “some or all” of them, again suggesting that this is to determine (in)eligibility first as a means to reduce time spent on the phone. The questions themselves are brief, and also only contain space for brief answers, which would logically require the healthcare professional filling out the form to make decisions about what to include and what to exclude. The questions are about admission history, past medical history, patient medications, presence of antibiotics, white blood cell count, temperatures, bacteria cultures in the blood, sputum and urine. There are small tables to fill out regarding most of this information, followed by check-yes-or-no type questions regarding active sepsis, chest x-rays and diabetes.

The TGLN file number must also be noted at the top of the second page. Before the next set of questions, there is a statement indicating there are just a few more questions left. The questions then commence with inquiries about name of the family physician and the physician who pronounced death, if this is a coroner’s case or if there is an autopsy pending, and the height and weight of the patient. Two tables follow with space to indicate the type and amount of IV

fluids and blood received by the patient in the hours before death. “Thank you for your time” is written in large font at the bottom of the second page, followed by a reminder of confidentiality and proper handling of the document in small italicized font, meaning that it is to be either kept or disposed of according to hospital policy.

Frequently Asked Questions for Healthcare Professionals

This document is similar to the *Routine Notification for Designated Hospitals* text in that it is done, as the name implies, in question-and-answer form. It is not, however, a brochure-style document and goes into further depth. All of the answers are also presented in bullet-form. The top banner of the first page is a set of pictures that depicts doctors and nurses at work. The first question asks who is eligible to donate organs at death. The first bullet lays out the criteria: patients with non-recoverable injuries on life support. Later bullets reiterate the emphasis on neurological or brain death, although the “opportunity” to donate after cardiac death is present when a criterion for neurological death is not met. The word “opportunity” is repeatedly used in TGLN literature; a positive word suggesting favourable circumstances. In the *Frequently Asked Questions for Healthcare Professionals* document alone, “opportunity” is used nine times and appears on every single page. Throughout the four documents, the word “opportunity” makes 14 appearances.

The chances are slim; only 1.5 percent of patient deaths are deemed eligible for the donation of “solid organs,” which include the lungs, kidneys, heart, liver, bowel and pancreas. The second question involves tissue donation, whose donation opportunity is vastly higher. In fact, the answer explains that all patients have the “*potential*” (emphasis in original) to donate

tissue. The tissue referred to is the cornea of the eye, skin, heart valves and bones. Of significant interest is that I was instructed, in my TGLN trainings of medical staff at the practicum hospital, to draw attention to the primary recipient of tissue, burned firefighters. I would argue that this was to emphasize the positive value of donation.

Question three asks what the benefits of donation are for patients and families. There is no question posed involving risks, implying that this is a purely-positive experience for all involved parties. The answer refers to the gratitude families report after being given the opportunity to help others and create a positive legacy. The language here is both optimistic and affirmative, reminding us at the end of the answer that 93 percent of Ontarians support organ and tissue donation. Question four details the ways different tissue benefits transplant recipients.

The fifth question and answer address the importance of timely action by healthcare professionals in reporting patient death to TGLN. There is also a strong point made that “**prior**” (emphasis in original) to discussing withdrawal of life support with the patient’s family, TGLN must be notified. Any questions the healthcare professional may have regarding registered donation consent by the patient may be directed to TGLN. TGLN alone has access to the online database that contains the consent information of Ontario citizens.

Question six explains neurological death. This seems a bit unnecessary as this FAQ sheet is intended for healthcare professionals, however these succinct descriptions could serve as a useful reminder for those unfamiliar with the process of organ donation. The first part of the answer to seventh question is similar to question five in discussing protocol before approaching the patient’s family. The focus is namely that TGLN must be contacted. The second part of the answer is reminiscent of question one, reminding the reader that in order to donate organs, the

patient must be ventilated so that oxygen is travelling through the blood to the vital organs. The third bullet point refers to statistics (without giving any citations) which indicate a higher success rate when there is a “joint approach” to discussing donation with families between a TGLN coordinator and a “member of the healthcare team.” There are two interesting differences in this portion of the text, which are substantially different than the other texts examined. For one, the TGLN coordinator is represented here with a lower-case “C,” whereas elsewhere it has been represented with a capital “C,” potentially indicating less authority or perhaps a reduced hierarchy between TGLN representatives and health care professionals. The second is that there seems to be an emphasis on “working together” with the healthcare professional being referred to as team-members. This significantly deviates from the consistent messaging in the other texts, which clearly indicates that the TGLN is the only person to be in contact with the family and has all the decision-making power.

Question eight lists the conditions that may result in neurological death. Question nine delves into donation after cardiac death (DCD), where the decision to recover organs is rooted in cardiorespiratory criteria instead of neurological criteria. The answer stresses the need to contact TGLN before discussing withdrawal of life support with the patient’s family. Afterwards, if the patient is deemed eligible by TGLN, the possibility will be addressed with the family by a TGLN Coordinator. Only then should life sustaining therapies be ceased and under instruction from TGLN. In question ten, healthcare professionals are reminded of the various situations that would require a call be made to TGLN, such as checking for brain death or for DCD-potential patients, arranging to meet with the family to discuss the removal of life support. Healthcare

professionals are reminded yet again to call TGLN before approaching families with the subject of donation.

In question 11, the role of the coroner in the donation process is addressed again. A coroner may be called in to investigate certain deaths which require special consideration due to being suspicious or from non-natural causes such as a suicide or accident (Eden, “Calling the Coroner”). TGLN, the answer explains, requires permission from the coroner to recover organs and/or tissues, but it is made clear that this will be worked out between the Coroner’s office and TGLN.

The answers to question 12 go into further detail about the sequence of events should organ donation be a possibility after neurological death. The first step is, of course, to contact TGLN to determine “initial medical suitability.” Then two tests to determine the validity of neurological death must be performed by two different physicians. After the time of death is provided to the family, they are then approached by TGLN with the opportunity to donate. If families inquire about donation before death, a TGLN Coordinator “should be involved in this discussion,” the text explains. Alongside reminders that the patient is to remain ventilated and thorough testing is to be done by the hospital, is a statement that testing for infectious disease is conducted by TGLN. It is not clear why the hospital cannot be responsible for testing for infectious disease.

Important information is also given regarding the rights of the family during the donation process, according to the answer for question 12. The family is provided time to “say goodbye to their loved one” before life sustaining therapy is removed. They are also permitted to be present during the withdrawal of this life support. Brief information about the organ recovery process is

given: it will take up to four to six hours, and the ventilator will be turned off after removal.

Post-organ recovery, the family may ask to view the body, although arrangements and a special location must be determined at that time. If the family wishes, they will be contacted by TGLN after organ recovery. A thank you note will be sent in appreciation of their “gift.”

Question 13 predictably moves into the tissue donation process. Again, the first step is to notify TGLN within an hour of death. TGLN is also to be notified if the family inquires about donation or if there is a specific hospital policy which requires contact be made. After the initial call, and if preliminary eligibility for tissue donation is accepted, a TGLN Coordinator (who the reader is reminded is a “specialist in the area of both donation and speaking with families”) will be put on the phone with the family before they leave the hospital. If that is not possible, contact information for the family will be provided to TGLN so that they may contact them outside of the hospital. After further information is collected by TGLN, the deceased patient’s body can be moved to the morgue until recovery is arranged. The cornea of the eyes may be recovered before transit to the morgue on the original unit where death was pronounced. The last few bullet points are very similar to that of the organ donation procedure; the family will be contacted by TGLN after recovery if requested, and a thank you note will be mailed.

The penultimate question addresses communication between donor families and the families of the recipient of organs and/or tissue. There is no direct communication, the answer explains, as the identity of all parties is kept strictly confidential. It is noted that they are protected under the legislation of the *Trillium Gift of Life Network Act*. However, donor families and recipients may exchange letters with one another, so long as they are anonymous. To ensure anonymity, the letters must first be sent to TGLN who will screen them for identifying

information before delivering them to the recipient. It is suggested that this correspondence is positive and comforting for both parties. The final question is simply a list to obtain further information regarding organ and tissue donation in Ontario. The two phone numbers are presented again, as well as the official TGLN website, the *Routine Notification in Ontario Hospitals* on-line manual, and it is indicated that other education materials are also available upon request.

V. DISCUSSION

This section will provide an in-depth discussion of the various themes derived from the preceding results piece. The three dominant themes I will be addressing are gatekeeping, positivity, and the reinforcement of discriminatory societal norms. I will then link these themes back to some of the theories explored in the literature review. Efficiency and the importance of timing were additional themes I deduced from analyzing the texts. TGLN frequently suggested that the forms, such as the *Routine Notification* and *Next Steps* worksheets, would not require much time to complete and assured in some instances that only a few questions remained. As organ and tissue procurement is time-sensitive, there were also specific guidelines for healthcare professionals on when to contact TGLN. However, exploring these themes with more depth is beyond the scope of this paper.

Gatekeeping

The predominant theme throughout the documents examined in the previous results section is the persistent gatekeeping efforts that permeate the primary TGLN texts used by nurses and other healthcare professionals. As noted earlier, the four texts selected for study are the central texts these healthcare professionals engage with in regard to OTDT processes at hospitals across Ontario. Throughout these documents there is a clear focus on the imperative for the healthcare professional to relinquish all control to TGLN during this process. TGLN is to have near absolute authority over every aspect of the OTDT process at Ontario hospitals, including contacting the Coroner. The only facilitative role that the healthcare professional seems to have is to alert TGLN to the possibility of donation. There is a single instance where the texts refer to the TGLN representative working with the healthcare professional as “team members” (see document 4, *Frequently Asked Questions for Healthcare Professionals*), but beyond this one reference there is no other indication in the texts that a healthcare professional’s purpose in the OTDT process is anything other than to signal TGLN that a donation is possible.

One of the primary ways TGLN establishes this control over the process is the repeated direction to call TGLN. For example, TGLN must be called whenever a patient (aged 79 and younger) dies in the hospital. TGLN must be called within one hour of that death, and even in anticipation of death, if possible. If the family of a patient inquires about organ donation, the healthcare professional is strictly instructed to *not* engage with the family on the matter and instead inform them that a “Coordinator” (from TGLN) would be available to discuss it with them. At no time is the healthcare professional authorized to discuss donation with families, and great care is taken to ensure this does not occur.

This requirement is so strictly enforced that, even when connecting families with TGLN, the healthcare professional is instructed to simply tell them a “Coordinator” (rather than a TGLN coordinator), is available to talk with them to discuss some of the decisions that need to be made as a “part of end-of-life care.” Healthcare professionals are not to indicate in any way that this is in regards to donation or that the Coordinator is an employee of TGLN. The reasoning behind this, as explained to me during my hospital placement by nurse clinicians working with TGLN and a TGLN hospital representative, is that if the healthcare professional were to say it is a “TGLN Coordinator” on the phone, the family may ask what TGLN is, which would inevitably lead to a discussion where the healthcare professional begins to discuss donation with the family.

There is also significant attention drawn to the fact that TGLN’s strict rules are enforceable by law via the *Trillium Gift of Life Network Act*. This act is mentioned numerous times in the texts and serves as a constant reminder that TGLN’s instructions are not simply suggestions, but are legally binding directives mandated by the Government of Ontario. In other words, it is emphasized in the texts that the OTDT referral procedure, as outlined by TGLN, is not something healthcare professionals can divert from, a point that was reinforced by repeated mentions of provincial legislation. During my placement in the hospital, I was also instructed to remind nurses that death and donation numbers are collected by TGLN and forwarded to the Ontario government, which seemed to suggest that failure to comply with TGLN’s protocol would be documented, however there is no direct mention anywhere in the texts what the consequences may be if individual healthcare professionals do not comply.

Positivity

The second notable theme from the reviewed TGLN texts is the concept of positivity. The language utilized by TGLN portrays OTDT processes as explicitly—and exclusively—positive. Families are given the “opportunity” to donate, according to TGLN, and as previously mentioned, they repeat this notion 14 times throughout the selected texts. Donation of organs and/or tissues is called a “gift” and a way to “honour” a recently-passed loved one. These words choices appear to be strategically employed to emphasize the positive, beneficial, and helpful aspects of donating organs and tissues, while avoiding some of the more challenging parts of death and donation.

Further, in the *Routine Notification for Designated Hospitals* brochure, one of the questions specifically discussed the positive effects of donation on a family’s grief. The question, itself, assumes that the family will donate and does not mention the possibility that a family may decline. In addition, there is no subsequent question inquiring about how being asked to donate may impact a family’s grief, especially if their decision is not to donate . The question is leading in the sense that there is really only one possibility provided (i.e., that the family will donate and that this will be positive), and this obscures the variety of responses that could be made by families who are being asked about donation. The theme of positivity is further reinforced in the text when uncited studies are referenced that conclude donor families are grateful for the opportunity to donate. Then the answer that is provided to the question how donation impacts a family’s grief states that donation is the chance at something positive in a situation that is, in all other respects, negative. Donation is presented as a means of honouring the “dying wishes” of their loved one and assumes that a) the deceased patient invariably wishes to become a donor,

and b) that this desire was a “dying wish” made as a final request before death. Conjuring up the significance of a dying wish is a weighty attribution to apply to organ and tissue donation.

Unlike other types of wishes or requests, a dying wish is culturally symbolic of being the final, and by association, perhaps the most important decision of an individual’s life. By implying the decision to be a donor is akin to a dying wish, TGLN is likely trying to give the significance of donation more impact.

Interestingly, what is mentioned next are instances of donating tissue: “The opportunity to help others in need of lifesaving skin transplants for burns, tissue for sight, or mobility resorting transplants (bone) is often comforting for grieving families” (*Routine Notification for Designated Hospitals*). One of the observations made when examining the four documents is that TGLN often emphasizes tissue donation over organ donation. The chances of a patient qualifying for organ donation are low, only 1.5 percent, while the possibility of tissue donation is exponentially higher. Although no specific figure is given to support this difference, tissues do not require ventilation from life-sustaining therapeutic machines, and thus the likelihood of being able to successfully donate tissue becomes far greater.

TGLN must submit annual reports to the Government of Ontario to demonstrate effectiveness of their organization and the associated legislation (TGLN, “Public Reporting.”), so it is reasonable to consider that a possible motivation behind emphasizing tissue donation is that doing so has the potential to produce better year-end numbers for TGLN. Furthermore, tissue transplantations are less complex than organ transplantations, and keeping with the theme of positivity, TGLN seems to focus on the successful and optimistic aspects of donation, while obscuring the more challenging and complex components. This is especially true considering that

organ transplantation procedures are often done to save a patient's life, whereas tissue transplantation can only enhance patient life. The stakes for unsuccessful organ transplantation, then, are much higher than they are for tissue transplantation, and failures can result in patient death, a reality that is never mentioned in the primary TGLN texts.

Another way in which TGLN presents a one-dimensional image of positivity is in the way the potential recipients of organ and/or tissue donation are constructed. For example, during my hospital placement it was suggested that I mention two particular scenarios involving recipients of organ and tissue donation. One was that a small child in Ontario had recently undergone a successful hand transplantation procedure. As mentioned in the previous results section of this paper, the other was to note that the primary recipients of donated tissue were firefighters who received skin grafts for burns sustained on-the-job. There are specific cultural assumptions and images invoked here; one being the innocence of a young child and the other being the brave, self-sacrificing firefighter. This produces a particular narrative about who is a deserving donation recipient, of which I suspect the intended goal is to make a strong case for donation.

This focus on particular kinds of organ and tissue recipients is congruent with narratives elsewhere in the transplantation community literature. A common trope is that we *must* donate organs, because people are in need of them, and these individuals deserve our help. For example, wealthy Westerners may travel abroad to purchase organs from the relative poor because their need has been justified by their personal plight of end-stage organ failure. Yet, there is very little recognition of donors and their suffering in any of these accounts. Moreover, there is no discussion in the literature of those in need of donation who may not be so clearly recognized as

‘deserving’. For example, what if instead of burned firefighter, the potential recipient of a skin graft was a sex worker who had been burned by her client, or a ‘terrorist’ who had an accident while making a bomb in her basement? These contrasting examples show how the concept of a worthy recipient has instead been socially constructed. Similarly, there is a social construction of donors. Sharp (2002) challenges the ‘myth’ that organ donors are generally middle-class white youth who suffer irreversible brain damage in highway accidents (p. 146). In fact, notes Sharp, many donors are the victims of suicides and homicides, often involving hand guns. Discourse surrounding the ethnic identities of donors has been whitewashed, omitting the young men of colour who live in marginalized inner-city neighbourhoods and are subjected to gang violence (Sharp, p. 147). This will be explored further in the next section on processes of othering.

By making the different types of donors and recipients invisible, TGLN’s literature and training materials do nothing to challenge these typical conceptions of the deserving and undeserving. Thus, intentionally or otherwise, when TGLN routinely uses positive language and refers to the plight of those waiting for a donation, they make the complexity of donation invisible. I would argue that they especially obviate the complex and difficult situation faced by families of deceased patients. These family members simultaneously have to deal with the grief of losing a family member and are asked to donate organs and/or tissues. TGLN presents this situation as solely an opportunity to create meaning in a time of loss, as if though there were no other possible reactions or responses to being asked to donate. In the texts, it is framed as if everyone is in favour of donation. The nuance of grief, ethics, and questions around who is deserving of organs and tissues is hidden from view in the texts examined for this project.

Moreover, TGLN appears to be concerned with some ethics and not others, and this can be gleaned by examining what is spoken about in the texts versus what is made invisible, both of which tie in with the themes of positivity and gatekeeping. For example, there is almost no discussion of a family choosing not to donate. The sole instance was discussed in this paper's results section where it was mentioned that if the family indicates to a healthcare professional their disinterest in donation, and this is reported to TGLN, TGLN may still contact the family "to ensure the family had the information needed to make an informed decision" (*Routine Notification for Designated Hospitals*). This appears to have some inconsistencies with TGLN's emphasis on donation being made in the spirit of giving (rather than coercion). It seems reasonable then to conclude that while TGLN wants the family to truly be comfortable with the decision to donate, there may still be considerable pressure placed upon families to donate during their time of grief immediately following the death of a loved one.

Processes of Othering

As alluded to in the previous section, the language employed by TGLN in these texts socially constructs both the donor and the recipient, in effect painting individuals as either 'deserving' and 'undeserving' of organs and tissues. Those with organ failure, for example, are constructed as more deserving of the organs than the deceased patient, who no longer has a use for them. Earlier it was noted that victims of gang violence constitute a significant portion of the donor pool. Transplant discourse in general, including that of TGLN, may avoid this discussion for a variety of reasons, but as one organ recipient and woman of colour (as cited in Sharp, 2002) explained, "they [that is, transplant professionals] just assume that violence is a way of life for

us” (p. 147). Sharp (2002) also points to the attitudes of medical examiners who release cadaveric organs from deceased patients who were victims of gang violence and are thus implicated in criminal investigations (p. 147). The concept of ‘social transformation’ is widespread among transplant professionals in regard to these types of donors, and donation in these instances is seen as justified because they allow an “otherwise unproductive person” to be rescued for “the common good” (Sharp, p. 147).

The TGLN texts reviewed in this paper make frequent connections between donation and the receiver, whose life is “saved” or “transformed” through receiving “the gift of life” (*Routine Notification for Designated Hospitals*). TGLN frequently pulls on gift relations theory, a concept developed by French sociologist Mauss in the 1920s, as evidenced in their agency name as well as the continual reference to ‘giving the gift of life’ throughout their texts (Gill and Lowes, 2008, p. 1608). Gill and Lowes (2008) observe that although the concept of gift theory and gift relations is pervasive in organ transplantation literature, there is underwhelming empirical evidence to support the relevancy of this framework to OTDT (p. 1608). For example, Mauss (as cited in Sque and Payne, 1994) argues that in true gift relations, “the obligation of a worthy return is imperative” (p. 46). TGLN, and similar organizations, who employ gift relations theory to advocate for organ and tissue donation are drawing their own conclusions that donation is equally beneficial to giver and receiver, a conclusion that has not been adequately supported (Gill and Lowes, 2008, p. 1608). TGLN claims that “donation provides a family with something positive in an otherwise negative life situation” (*Routine Notification for Designated Hospitals*). So while organ and tissue receivers are ‘given the gift of life,’ donors and donor families are

expected see the exchange as positive and having equivalently worthy benefits, in all cases promoting the idea that the receiver deserves the donation.

The advancement of the language of gift relations in TGLN's literature is further complicated by the realization that the gift relationship cannot be fulfilled with donations from deceased donors, which TGLN exclusively relies on for organ donation (citing either NDD or DCD determinants of death). Sharp (2000) argues that this language may conceal capitalist methods of commodification (p. 292). It should not be assumed that TGLN's reliance on altruistic donation exempts them from the machinations of capitalist society, and indeed through advocating for organs as gifts to give and receive, TGLN has fashioned the human organ as product; a good of human origin. Sharp notes that two types of commodification may simultaneously be at work, one referencing Mauss's conception of 'gift' and 'reciprocity' as symbolically infused, and the other alluding to Marx's understanding of commodities as goods manufactured within the isolating environment of capitalism (p. 292). Medical professionals and organizations like TGLN may advocate for the objectification of body parts, including organs, while nonprofessionals may read human organs and tissues as permeated with bodily integrity, selfhood, and kinship. "Thus," Sharp explains, "Mauss and Marx can work in tandem, together generating a dialectical mode of commodification as social process" (p. 292).

Anonymous altruistic donation—culturally recognized as an act of extraordinary social kindness—is the foundation on which TGLN organizes all its activities, yet Fox and Swazey (1992) are able to illuminate the darker side to this understanding. They claim recipients of organ donation often feel a strong sense of obligation to "repay" their donor (Fox and Swazey, p. 40). This weighs heavily on recipients and develops into a significant moral and psychological

burden. However this act of extraordinary kindness, giving the gift of life, is intrinsically unreciprocal, making the quest to reciprocate as advanced in gift theory impossible. This realization only further contributes to the tormenting burden felt by recipients to somehow repay or compensate their donor. Fox and Swazey refer to this characteristic of the gift exchange features of transplantation as the “tyranny of the gift” (p. 40). This still holds true in cases of deceased donation, such as those arranged by TGLN, as the recipient will transfer the urge to repay the donor to an urge to repay the deceased donor’s surviving family (Fox and Swazey, p. 40). Given that the surviving family plays a key role in organ donation processes under the current structure in Ontario maintained by TGLN, truly it is the donor family who has given the gift of life, and therefore recipients may seek in futility to compensate an anonymous group of people. To illustrate this, Fox and Swazey cite an interview they conducted with a man who discussed his experience after receiving a kidney from a deceased donor he only knew to be a nine-year-old girl (p. 41):

Ever since the transplant, I have a recurrent dream. It’s not about the little girl, but about her mother... in my dream, I see this woman, all dressed in black, with a black veil over her face. She is crying, and she has reproach in her eyes. I try to communicate with her, to console her, but I can’t. Because there is a pane of glass between her and me: a pane just like the one that was in the isolation room where I was hospitalized during the first days after the transplant...”

Despite the many conflicts associated with invoking gift theory in organ transplantation practices, TGLN centres itself squarely around this concept. Indeed, TGLN is but an acronym for “Trillium Gift of Life Network,” thereby fashioning itself as a matrix of gift relations in action,

when in fact the gift theory may not hold any relevancy. Sharp (2000) contends that the culture of biomedicine is replete with “mystified commodification,” prominently exemplified in the frequent iteration of organ donation as a “gift of life,” which she explains originated in the blood industry and is now used to illustrate surrogacy as well (p. 303). TGLN’s appropriation of gift theory is further problematized by the recognition that OTDT is a multi-million dollar medical industry, both in Canada and across the world (Sharp, p. 304). When the rhetoric for referring to brain dead or DCD *patients* shifts to *donors*, a perception of human bodies as recycling products prevails. Policy makers in the field of OTDT work collectively and insistently to create a culture that understands donation as inherently a “gift of life,” while simultaneously employing a variety of marketing strategies to increase the supply of organs for an insatiable demand (Sharp, p. 315).

Another reality that is hidden in the one-dimensional narrative put forward by TGLN is the variability of deceased-patient family responses to being asked to donate. Some families may not consider the potential exchange positive or beneficial, further nullifying the applicability to gift relations and gift theory. Indeed, decisions *not* to donate by family members are complex, and not simply a matter of failing to recognize that the dead do not “need” their organs any longer. OTDT health campaigns, such as those produced and endorsed by TGLN, often focus on educating the general public and healthcare professionals about the “facts” of OTDT (Moloney and Walker, 2002, p. 299). However, decisions not to donate by individuals or their families are often rooted in religious or cultural beliefs, rather than in a lack of ability to understand the function of organs and tissues (Moloney and Walker, p. 307). There is no mention anywhere in the TGLN texts I examined that such beliefs may influence a decision to donate, thereby making them invisible by leaving them out of the narrative. In this way, TGLN not only creates a state of

otherness, but goes further and makes the “other” invisible. Through presenting enthusiastic consent not only as the norm, but purportedly the *only* response to donation inquiries, families who decide not to donate are obscured in the discourse developed by TGLN.

Though it may not be intentional, the “Call-Screen-Connect” process described in the texts I examined also creates an environment that facilitates the marginalization of certain groups. As I will demonstrate, in addition to othering individuals and families who decline to donate, homosexual and bisexual men appear to be excluded from the donation pool. TGLN repeatedly states that sexual orientation is not a barrier to donation. See, for example, “Frequently Asked Questions: General” section of their official website, www.giftoflife.on.ca, where an answer about who can register to be a donor says that factors such as sexual orientation do not prevent individuals from becoming donors. Yet what is not addressed in TGLN’s publicly available documents, including the four texts I examined, is that while a queer orientation itself does not affect potential to donate, being sexually active in particular relationships does have an impact, especially for men who have sex with men (MSM).

This is known to the Canadian public because TGLN has discussed their position with the media in a limited capacity, clarifying to the press that although a potential donor’s sexual orientation is not a conclusive factor in determining (in)eligibility, it does influence the final decision (“Organs donated by gay man rejected,” CBC News). TGLN’s president and CEO Ronnie Gavsie explained the policy, saying that TGLN follows Health Canada legislation by placing queer individuals in the high-risk category, however “that fact alone would not preclude them from being a donor.” Health Canada’s policy, which also influences decisions about MSM donating blood, specifies that any male who has had one or more sexual encounters within the

past five years with another male would not be eligible to donate organs, tissues or blood (“Organs donated by gay man rejected,” CBC News). Carole Saindon, a spokesperson for Health Canada spoke to this issue in 2008 when it was newly imposed, insisting “this requirement is related to the risk of the activity and not a person’s lifestyle or sexual orientation.” Previously, MSM were banned entirely from donation (“Health Canada clarifies organ donation policy”, CBC News).

There has been considerable opposition to Health Canada’s policy on banning MSM from donation, particularly from LGBTQ rights groups. Executive director of gay-rights advocacy group Egale Canada Helen Kennedy argues that this deferral process is antiquated. “It’s still a discriminatory process,” she contends (as cited in Andreatta, 2013,). Kennedy is critical of the five-year deferral policy, as the advances made in testing for infectious disease make barring MSM from donating unless they have been celibate for half a decade outdated. “It’s no different than an indefinite deferral,” she concludes (as cited in Andreatta, 2013). Prominent American pathologist Vamvakas has advocated against the donation policy in the United States which bans MSM from blood, organ and tissue donation *for life*. He believes that policy makers have exercised a selective caution in the treatment of MSM that is not evidence-based. “In the absence of evidence of a consistent approach to safety,” Vamvakas contends, “maintenance of the current MSM deferral cannot be scientifically justified.” He goes on to say that the risks associated with donations from MSM are “very, very small, much smaller than other risks that currently are implicitly or overtly accepted” (as cited in. in Roehr, 2009, p. 1).

During the 1980s, when fears about HIV were at their highest, Western societies responded by enacting sweeping laws which banned homosexual and bisexual men from

donating organs, tissue and blood. At this time, there was limited information on HIV: testing was rudimentary at best and non-existent at worst, the disease was considered exclusive to the queer male community, and a diagnosis was as good as a death sentence. This pervasive fear of HIV transmission has been the catalyst for the creation and continued support of laws such as the ones passed by Health Canada. Biomedical journalist Roehr (2009) believes the laws surrounding MSM donation have not kept up with the science. He claims homophobia has been entrenched in these policies from the start, as there is no consideration of a male in a monogamous relationship with another male or distinguishing between sexual acts which have varying risks (p. 1). He echoes Vamvakas' concern that the plausibility of homophobia being at the root of these donor-exclusionary laws is augmented in light of less-restrictive policies for female prostitutes and injection drug users (Roehr, p. 1). To make his point, Roehr notes that black women have a HIV prevalence that is 17 times that of white women, yet there is no policy stipulating differing deferral-times. He suggests this is because society is more conscious of racism than homophobia (p. 2).

In terms of the texts analyzed for this project, I was surprised that there was not a single mention of the influence of a patient's sexual history on donation (in)eligibility. The *Routine Notification Worksheet* has a section to denote presence of infectious disease such as HIV, but questions involving the patient's sexual history are not explicit in the forms. A logical conclusion is that these more sensitive (and perhaps potentially discriminatory) questions are addressed in conversations between TGLN and the patient's family, constituting another example of gatekeeping. This conclusion is supported by evidence in reports to the Canadian press by the family members of deceased gay and bisexual men in Ontario.

One of the more notable cases involves a young gay man from Windsor, Ontario. In August 2012, 23-year-old Rocky Campana attempted suicide and was treated at a hospital for two days before life-sustaining therapy was removed. As we know from explorations in the results section of this paper, patients on life support are ideal candidates for organ donation. Campana was a healthy individual, and by all accounts considered low-risk by TGLN and Health Canada standards save for the fact that he was a sexually active gay male (“Family looks to change restrictions,” CTV Windsor). His parents, Nancy and Rob Campana, approached the Canadian media about their experience with a TGLN Coordinator after the death of their son. Nancy explains that she was pointedly asked if he was a gay male, and then asked if he was sexually active, both of which she confirmed. Then the “tone of the conversation changed,” Nancy recalls. The Campana family was later told Rocky’s organs and tissues were not eligible for donation.

In addition to drawing attention to potentially discriminatory practices within the process of OTDT in Ontario, this story also reveals the negative impact on a family who is told their loved one is high risk and therefore ineligible for donation. Nancy describes the moment she got off the phone with TGLN to tell Rocky’s family and friends that he was deemed ineligible for donation, saying “many of them broke down.” Distraught, his gay friends said to her, “Nancy, we can’t donate blood; they’re not going to take our organs” (“Organs donated by gay man rejected,” CBC News). The impact of being deemed ineligible is a reality which is hidden from the discourse around donation presented by TGLN in the texts that were examined. Significantly, many families speak to a TGLN Coordinator before leaving the hospital after the death of a

loved one, yet there is no material provided by TGLN to assist healthcare professionals in dealing with families who have been denied donation.

Moreover, there remains something troubling about TGLN's omission of the issue of sexual activity in their materials for healthcare professionals. Families of deceased MSM patients are both othered and marginalized by way of a questionable policy that is not even explained or addressed in the texts provided to professionals, and this absence embodies a concerning theme. Health Canada has indicated that organs from MSM can still potentially be donated, provided the recipient is "aware of the risk and gives consent" (CBC, 2008, "Health Canada clarifies organ donation policy"). This is a national policy which the provinces are free to apply as they see fit, but I have not come across any documentation on whether TGLN adopts or rejects this policy. Even if TGLN were to adopt the policy, there is little to suggest individuals awaiting a transplant would be able to make a scientifically-informed decision and may instead draw on social stigmas against MSM, making TGLN an indirect yet complicit actor in systems of homophobia. For an organization that stresses the importance of families having all the right information before making a decision, allowing them to potentially deny a donation based on a highly disputed justification that is quite likely rooted in homophobia, is troubling.

VI. CONCLUSION

Perceptions on donation and transplantation have been, and continue to be, in flux since the time they entered the realm of ethical debate following the first successful operations in the 1960s (Price, 2000, p. 23). These understandings of organ and tissue donation and transplantation (OTDT) are largely dictated and influenced by time, place and social discourse. Such beliefs

include assumptions about donation as a universally positive opportunity to “give the gift of life”, as repeatedly put forth in TGLN’s texts or, for example, that autonomy of the body and individual choice supersede concerns about exploitation in donor-receiver relationships, as insisted by Cherry (2009, p. 651-52) and Wilkinson (2011, p. 20). Over the course of this paper, I have sought to explore some of these convictions and critically analyze the pervasive beliefs that permeate Canada’s OTDT environment. I began with recognizing unprecedented new ethical concerns that arose out of the medical marvel of transplantation, including concerns about the consequences of targeting the poor as sellers as a means to alleviate their poverty, implications of donation for altruism, applicability of gift relations and gift theory, how to effectively obtain and allocate sufficient supply, and who is deserving and undeserving of the organs that have become a new form of “commodity fetishism” in legal and illegal markets around the world (Scheper-Hughes, 2003, p. 1645).

Moreover, I review scholars who argue that the phenomenon of transplant tourism is directly related to the inadequate managing of organ and tissue supply in the home country of the patient who travels abroad to purchase an organ. Furthermore, I address the concept of invented scarcity perpetuated by the current culture of biomedicine and the long-standing human quest for immortality, the combination of which understands medical intervention to prolong human as imperative. I have grounded this project in the assumption that the commodification of organs exacerbates existing inequalities, and in the case of living organ donation, constitutes a form of bioviolence against the poor (Moniruzzaman, 2012, p. 87). The relationship between privilege and power is also presented as having a particular significance for OTDT, an association that holds relevance in both legal and illegal systems. These frameworks have been informed by

numerous other studies into the realities of impoverished persons in Global South countries who are coerced in a variety of ways to either give or sell one of their kidneys.

Rather than supplement the well-developed body of knowledge on the supply side of illegal organ markets, I chose to investigate the demand from Canadian patients. From this standpoint, I was able to observe the concerning state of Canadian OTDT systems, ones which have caused patients to lose faith in legitimate transplantation networks here in Canada and look for alternative means of obtaining life-saving organs elsewhere. The 2011 Canadian strategic plan *Call to Action* specifically expressed that one of its primary goals is to “ensure patients can expect safe and timely transplant solutions here at home,” thereby counteracting transplant tourism and the exploitation of poverty-stricken communities outside of Canada (p. 160).

As the provinces and territories each work to improve their struggling OTDT systems, Ontario has enlisted Trillium Gift of Life Network (TGLN) as an agency of the provincial government charged specifically with this task. TGLN’s significant influence on and even control over much of the OTDT discourse in Ontario holds them at least partially responsible for the attitudes of Ontarians towards donation, their willingness to register to be a donor, and their participation in transplant tourism. TGLN has drafted, and is in the process of carrying out, a promising three-year strategy for achieving sustainability, increasing the rate of organ and tissue donation, and expanding the number of registered donors in Ontario. In this study, I have taken an in-depth look at four of the primary texts produced by TGLN to inform and assist healthcare professionals in facilitating this three-year strategy. The prominence of these texts in the daily work lives of Ontario medical professionals was partly informed by a work placement at a

Southern Ontario hospital during the period immediately before and after a hospital-wide implementation of TGLN's new guidelines for patient death.

For this specific research project I conducted a discourse analysis on these forms and discerned three major themes. The first theme was gatekeeping, where TGLN takes complete control regarding asking families about organ and tissue donation away from healthcare professions and insists that the conversation about donation remain exclusively under their jurisdiction. The second theme was positivity, where the response of families who are asked about donation after the death of a loved one is presented one-dimensionally, as though it is the invariable norm for the surviving family to view donation as an opportunity to create meaning in a time of loss. This makes the spectrum of experiences, which include declining to donate and being ineligible for donation, hidden from the discourse. The third, and final theme, I examined in-depth is processes of othering involved in OTDT in Ontario, which rely on (and subsequently reinforce) social constructions of certain individuals as 'deserving' and others as 'undeserving' of organs and tissues. There is an emphasis on the types of people expected to donate and receive organs and tissue, which aligns with established social norms about 'worthy' members of society.

A particular group of people excluded from these texts is the gay and bisexual male community. There is no mention in any of the publicly-available TGLN texts of the effect disclosing that a potential donor is a man who has sex with men (MSM) has on eligibility, yet we can infer there are strong policies in regard to this based on reports made to the media by family members. Despite extensive testing for infectious disease, MSM appears to be seen as a proxy for high risk sexual activities, which is problematic in its unfoundedness and potential roots in

homophobia and biphobia. Therefore, there is significant cause for concern regarding TGLN's handling of the Health Canada policy against MSM donations. By not seriously engaging with questions of the legitimacy and necessity of its five-year requirement of celibacy for gay and bisexual men, and potentially leaving the decision to receive an organ from a MSM up to a patient on a transplant wait list, TGLN's silence makes room for discrimination based on sexual orientation.

These problematic themes are worth exploring because TGLN has an incredibly important task, one that has ramifications beyond Ontario and even beyond Canada. I have posited in this paper that for a successful and ethical solution to the organ crisis in Canada, we must resist a commodified system. I remain unconvinced that the inequities observed in currently operating illegal networks for organs would not be reinstated in a government regulated organ market. Furthermore, introducing a system where ability to pay replaces magnitude of need is in conflict with Canada's Medicare program, which was established to prevent the allocation of health care services based on relative wealth. TGLN upholds this principle and emphasizes the value in altruistic donation. If successful, TGLN could lead the way for improving systems of OTDT in Canada. However, the concerning themes I have identified can be understood as barriers to the success of TGLN and thus impede its efforts to increase donation, develop adequate infrastructure with which to effectively procure and allocate organs and tissues, and reduce incidence of Canadian patient participation in transplant tourism.

Moving forward, TGLN ought to also consider the necessity of their extreme enforcement of gatekeeping and allow healthcare professionals to have more relevance in the donation procedure, such as trusting a nurse who informs TGLN a family is absolutely not

interested in donation. TGLN should be cautious that in its championing of positivity, it does not obscure the complexity and significance of organ donation. There ought to be a dedication to patient and patient-family care regardless of the decision to donate, and by presenting donation as a universally positive experience, TGLN may inadvertently be putting undue pressure on families while simultaneously perpetuating negative stereotypes about those who decline to donate.

Similarly, TGLN should be attentive to processes which may be othering and to the problematic social construction of the ‘deserving’ and ‘undeserving’ of organs and tissues. By providing no counsel in the most commonly-used forms by healthcare professionals working with TGLN’s legislation for circumstances in which a family declines to donate, the existence of these individuals is erased and nurses have no guidelines with which to inform their care. I also recommend that TGLN proceed with a reduced emphasis on gift relations and gift theory and strategize a more appropriate means of advocating for donation.

Finally, I would advise TGLN to dramatically increase its transparency with the public in regard to MSM donations, and challenge Health Canada to reconsider their policy against these kinds of donations. By addressing these concerns, TGLN could evolve into an organization that truly advocates for the overall health of Ontarians. By relinquishing the objective of simply increasing organ and tissue donation within the province, TGLN could replace this preoccupation with an objective to provide the best care possible for all patients and their families in Ontario who interact in some way with the OTDT system, be it as donors, receivers, or even as those who decline to donate.

The conclusions of this study demand further analysis of TGLN and other OTDT strategies in Canada. Possible areas of research to better understand TGLN's practices include an exhaustive discourse analysis of all TGLN texts and interviews of healthcare professionals in Ontario or employees of TGLN, each of which the time constraints of this project did not allow. More time and energy needs to be spent understanding the conditions which motivate patients to turn to illegal markets for organs, shifting the focus from the Global South countries where organs are bought to our own backyard, where demand originates and distrust in established transplant systems compounds, bearing tragic and unjust consequences on a global scale.

References

- Altman, J. (2013). Organ Transplantation: The Need for an International Open Organ Market. *Touro Law Review*, 5, 61-183.
- Andreatta, D. (2013). Gay men celibate for at least five years now allowed to give blood. *The Globe and Mail*. Retrieved from <http://www.theglobeandmail.com/life/health-and-fitness/health/gay-men-celibate-for-at-least-five-years-now-allowed-to-give-blood/article12056857/>
- Bailey, A. (1998). Privilege: Expanding on Marilyn Frye's "Oppression". *Journal of Social Philosophy Augusta*, 29, 3, 104-119.
- Bailey, E. (1999). Should the State Have Rights to Your Organs? Dissecting Brazil's Mandatory Organ Donation Law. *The University of Miami Inter-American Law Review*, 30, 3, 707-726.
- Banks, G. J. (1995). Legal & Ethical Safeguards: Protection of Society's Most Vulnerable Participants in a Commercialized Organ Transplantation System." *American Journal of Law & Medicine*, 21, 1, 45-110.
- Becker, G. S., & Elías, J. J. (2007). Introducing Incentives in the Market for Live and Cadaveric Organ Donations. *Journal of Economic Perspectives*, 21, 3, 3-24.
- Beltrami, A. P., Cesselli, D., Bergamin, N., Marcon, P., Rigo, S., Puppato, E., D'Aurizio, F., ... Beltrami, C. A. (2007). Multipotent cells can be generated in vitro from several adult human organs (heart, liver, and bone marrow). *Blood*, 110, 9, 3438-46.
- Call to Action. (2011). *Canadian Organ and Tissue Donation and Transplantation Communities and Canadian Blood Services*. Retrieved from <http://www.organsandtissues.ca>

- Canada. Health Canada. (n.d.) Health Care System. Retrieved from <http://www.hc-sc.gc.ca>
- Canada. Health Canada. (n.d.) Canada's Health Care System (Medicare). Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/medi-assur/index-eng.php>
- Cherry, M. J. (2009). Why Should We Compensate Organ Donors When We Can Continue to Take Organs for Free? A Response to Some of My Critics. *The Journal of Medicine and Philosophy*, 34, 6, 649-73.
- Cohen, I. G. (2013). Transplant Tourism: The Ethics and Regulation of International Markets for Organs. *The Journal of Law, Medicine & Ethics*, 41, 1, 269-285.
- Cohen, L. R. (1989). Increasing the Supply of Transplant Organs: The Virtues of a Futures Market. *The George Washington Law Review*, 58, 1, 1-51.
- Cohen, L. R. (2001). The Other Kidney: Biopolitics beyond Recognition. *Body & Society*, 7, 9-29.
- Cohen, L. R. (2005). Directions for the Disposition of My (and Your) Vital Organs. *Regulation Washington*, 28, 3, 32-39.
- Cooper, M. (2008). *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era*. Seattle: University of Washington Press.
- Creswell, J. W. (2012). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Los Angeles: SAGE Publications.
- Davis, F. D., & Crowe, S. J. (2009). Organ Markets and the Ends of Medicine. *The Journal of Medicine and Philosophy*, 34, 6, 586-605.

- DeVault, M., & McCoy, L. (2006). Institutional ethnography: Using interviews to investigate ruling relations. In D. E. Smith (Ed.), *Institutional Ethnography as Practice* (pp. 15-44). Toronto, ON: Rowman & Littlefield Publishers, Inc.
- Eden, D. (n.d.) Calling the Coroner: A Guide for Health Care Professionals. In *General Surgery Resident Manual*. Hamilton, ON: McMaster University. Retrieved from http://fhs.mcmaster.ca/surgery/divisions/postgrad/GenSurg_RM_Chap31.html
- Epstein, R. (2006). "Kidney Beancounters." <http://online.wsj.com/news/articles/SB114765339774152572>
- Fox, R. C., & Swazey, J. P. (1992). *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press.
- Gill, J. S., Goldberg, A., Prasad, G. V., Fortin, M. C., Hansen, T. B., Levin, A., Gill, J., ... Caulfield, T. (2010). Policy statement of Canadian Society of Transplantation and Canadian Society of Nephrology on organ trafficking and transplant tourism. *Transplantation*, 90, 8, 817-20.
- Gill, P., & Lowes, L. (2008). Gift Exchange and Organ Donation: Donor and Recipient Experiences of Live Related Kidney Transplantation. *International Journal of Nursing Studies*, 45, 11, 1607-1617.
- Godderis, R. (2011). Iterative Generation of Diagnostic Categories Through Production and Practice: The Case of Postpartum Depression. *Culture, Medicine and Psychiatry*, 35, 4, 484-500.

- Goldman, C. (2012). Stanford philosopher examines why some things should not be for sale. *Stanford News*. Retrieved from <http://news.stanford.edu/news/2012/may/moral-limits-markets-052512.html>
- Hill, M. (2010). Organ Donation: You Decide Where Your Organs Go. *City Life*. Retrieved from <http://www.citylifemagazine.ca/health/organ-donor-ontario/6829>
- Hippen, B. E., & Cato Institute. (2008). Organ Sales and Moral Travails: Lessons from the Living Kidney Vendor Program in Iran. *Policy Analysis*, 614, 1-17.
- Illich, I. (1974). Medical Nemesis. *Lancet*, 1, 7863, 918-21.
- Jha, V., & Chugh, K. S. (2006). The Case Against Regulated System of Living Kidney Sales. *Nature Clinical Practice Nephrology*, 2, 9, 466-467.
- Matas, D., & Kilgour, D. (2007). *Bloody Harvest: Revised Report into Allegations of Organ Harvesting of Falun Gong Practitioners in China*. Falun Dafa Information Center.
- McCoy, L. (2008). Institutional ethnography and constructionism. In J.A. Holstein and J.F. Gubrium (Eds.), *The Handbook of Constructionist Research* (pp. 701-714). New York, NY: Guilford Press.
- McCoy, L. (2006). Keeping the institution in view: Working with interview accounts of everyday experience. In D. E. Smith (Ed.), *Institutional Ethnography as Practice* (pp. 109-125). Toronto, ON: Rowman & Littlefield Publishers, Inc.
- McNally, D. (2008). The Commodity Status of Labour: The Secret of Commodified Life. In G. Laxer and D. Soron (Eds.), *Not for Sale: Decommodifying Public Life* (pp. 39-54). Peterborough, Ont: Broadview Press.
- The Medical Care Act, 1966*. Canadian Museum of Civilization. <http://www.civilization.ca>.

- Moloney, G., & Walker, I. (2002). Talking About Transplants: Social Representations and the Dialectical, Dilemmatic Nature of Organ Donation and Transplantation. *The British Journal of Social Psychology / the British Psychological Society*, 41, 299-320.
- Moniruzzaman, M. (2012). "Living Cadavers" in Bangladesh: Bioviolence in the Human Organ Bazaar. *Medical Anthropology Quarterly*, 26, 1, 69-91.
- Nikander, P. (2008). Constructionism and discourse analysis. In J.A. Holstein and J.F. Gubrium (Eds.), *Handbook of Constructionist Research* (413-28). New York: Guilford Press.
- Novelli, G., Rossi, M., Poli, L., Morabito, V., Ferretti, S., Bussotti, A., Nudo, F., ... Berloco, P. B. (2007). Is Legalizing the Organ Market Possible? *Transplantation Proceedings*, 39, 6.
- Pease, B. (2010). *Undoing Privilege: Unearned Advantage in a Divided World*. London: Zed Books.
- Prasad, G. V., Shukla, A., Huang, M., D'A, H. R. J., & Zaltzman, J. S. (2006). Outcomes of Commercial Renal Transplantation: a Canadian Experience. *Transplantation*, 82, 9, 1130-5.
- Price, D. (2000). *Legal and Ethical Aspects of Organ Transplantation*. Cambridge, England: University of Cambridge.
- Richards, J. R. (2012). *The Ethics of Transplants: Why Careless Thought Costs Lives*. Oxford: Oxford University Press.
- Roehr, B. (2009). Should Men Who Have Ever Had Sex with Men be Allowed to Give Blood? Yes. *Bmj (clinical Research Ed.)*, 338.

- Roth, A. E. (2007). Repugnance as a Constraint on Markets. *Journal of Economic Perspectives*, 21, 3, 37-58.
- Satz, D. (2010). *Why Some Things Should Not Be for Sale: The Moral Limits of Markets*. New York: Oxford University Press.
- Scheper-Hughes, N. (2001). Commodity Fetishism in Organs Trafficking. *Body & Society*.
- Scheper-Hughes, N. (2003). Keeping an Eye on the Global Traffic in Human Organs. *Lancet*, 9369, 1645-1648.
- Scheper-Hughes, N. (2003). Rotten Trade: Millennial Capitalism, Human Values and Global Justice in Organs Trafficking. *Journal of Human Rights*, 2, 2, 197-226.
- Scheper-Hughes, N. (2004). Parts unknown: Undercover Ethnography of the Organs-Trafficking underworld. *Ethnography*, 5, 1, 29-73.
- Scheper-Hughes, N. (2005). Organs Without Borders. *Foreign Policy Washington*, 146, 26-27.
- Scheper-Hughes, N., & Wacquant, L. (2007). *Commodifying Bodies*. London: Sage Publications.
- Sharp, L. A. (2000). The Commodification of the Body and its Parts. *Annual Review of Anthropology*, 29, 287-328.
- Sharp, L. A. (2001). Commodified Kin: Death, Mourning, and Competing Claims on the Bodies of Organ Donors in the United States. *American Anthropologist*, 103, 1, 112-33.
- Sharp, L. A. (2002). Denying Culture in the Transplant Arena: Technocratic Medicine's Myth of Democratization. *Cambridge Quarterly of Healthcare Ethics*, 11, 2, 142-150.

- Shelley, L. I. (2010). *Human Trafficking: A Global Perspective*. Cambridge University Press.
- Shimazono, Y. (2013). The State of the International Organ Trade: a Provisional Picture based on Integration of Available Information. *Organ Donation*, 23-39.
- Smith, D. E. (2005). *Institutional Ethnography: A Sociology for People*. Walnut Creek, CA: AltaMira Press.
- Smith, D. E. (2006). *Institutional Ethnography as Practice*. Lanham, Md: Rowman & Littlefield.
- Sque, M., & Payne, S. A. (1994). Gift Exchange Theory: a critique in relation to organ transplantation. *Journal of Advanced Nursing*, 19, 1, 45-51.
- Taylor, J. S. (2005). *Stakes and Kidneys: Why Markets in Human Body Parts Are Morally Imperative*. Aldershot, Hants, England: Ashgate Pub.
- Trillium Gift of Life Network. (n.d.) About Us. Retrieved from <http://www.giftoflife.on.ca/en/aboutus.htm>
- Trillium Gift of Life Network. (2010). Donation Resource Manual. *Queen's Printer for Ontario*. Retrieved from <http://www.giftoflife.on.ca/en/professionals.htm>
- Trillium Gift of Life Network. (n.d.) Frequently Asked Questions: General. Retrieved from <http://www.giftoflife.on.ca/en/faq.htm>
- Trillium Gift of Life Network. (n.d.) What is Trillium Gift of Life Network? Retrieved from <http://www.giftoflife.on.ca/en/faq.htm>
- Urback, R. (2013). Canada's opt-in organ donation system isn't working. *National Post*. Retrieved from <http://www.nationalpost.com>
- Veatch, R. M. (2006). Why Liberals Should Accept Financial Incentives for Organ Procurement. *Kennedy Institute of Ethics Journal*, 13, 1, 19-36.

Wilkinson, T. M. (2011). *Ethics and the Acquisition of Organs*. Oxford: Oxford University Press, 2011.

Wright, L., Zaltzman, J. S., Prasad, G. V. R., & Gill, J. (2013). Kidney Transplant Tourism: Cases from Canada. *Medicine, Health Care and Philosophy*, 16, 4, 921-924.

APPENDIX: Trillium Gift of Life Network Texts

Routine Notification for Designated Hospitals (2 pages)

Routine Notification Worksheet (2 pages)

Next Steps Worksheet (2 pages)

Frequently Asked Questions for Healthcare Professionals (4 pages)

Why has TGLN asked healthcare professionals to avoid initiating the donation discussion with families?

Research indicates that experience and a person's comfort level in speaking to families about donation impacts both the family's experience and its choice to donate tissue. Under the *Trillium Gift of Life Network Act* regarding the discussion of donation, TGLN has the authority to specify the manner in which contact with the family is made. TGLN coordinators receive quarterly training in approaching families both by telephone and in person. As a result, the TGLN coordinators have higher positive consent outcomes than hospital staff when they approach families.

The ultimate responsibility for speaking with families belongs to TGLN. In situations where a healthcare provider indicates the family does not wish to donate, a TGLN coordinator may contact the family to ensure the family had the information needed to make an informed decision (e.g., a registered consent decision to donate by their loved one).

What if families ask about donation?

If a family asks about donation, tell family members that you are able to connect them with the donation specialists at TGLN to share more information with them.

How does TGLN determine if the person had a registered consent decision and how is this communicated to the family?

Only TGLN coordinators have access to the donation consent information in the OHIP database. When hospitals call TGLN and initial medical suitability is established, a call is made to access the registered information. If the consent to donate is registered, a TGLN coordinator provides the consent information to the donor's family members. Support is provided to the donor's family members to help them understand the decision their loved one has made to save and transform lives and what the donation process entails.

Providing clinical information to TGLN can take some time. How can I minimize the amount of time on the phone with TGLN?

TGLN has organized the order of the clinical history questions and has worksheets available to help hospital staff streamline the process. This enables TGLN to determine if the person is eligible for donation for transplant, or research and teaching.



Are families informed if organs or tissues have been recovered for transplant or research?

Yes. If any organs and/or tissue are recovered, the family receives a thank you letter. If for any reason a donation does not proceed after consent, the donor family is contacted by TGLN to let them know and to thank the family for its generosity in consenting to the donation. TGLN also explains that all possible measures were attempted to recover the organs and/or tissue and honour their gift.

In Coroner cases, who will obtain the Coroner's approval for the donation process?

The provincial Coroners from the Coroner's Office of Ontario strongly support organ and tissue donations. If a potential donation case has been deemed a Coroner's case, the Coroner must be contacted and give permission for donation to occur. TGLN will speak with the Coroner to confirm permission.



Trillium Gift of Life Network

Contact Trillium Gift of Life Network Provincial
Resource Centre, available 24/7

1-877-363-8456 (Toll Free) • 416-363-4438 (Toronto)

For more information for healthcare providers
regarding TGLN and organ and tissue donation
in Ontario visit: www.giftoflife.on.ca

To register your consent, visit:

beadonor.ca



Frequently Asked Questions
For Healthcare Professionals

Routine Notification for Designated Hospitals



CALL



SCREEN



CONNECT

We have been told that to meet legislation requirements we now need to call Trillium Gift of Life Network (TGLN) when our patients meet referral indicators for high risk of imminent death and within one hour of time of death. What is this about?

Your hospital is a designated facility under Part II.1 of the *Trillium Gift of Life Network Act*. This legislation requires that designated hospitals meet the referral provisions detailed under Part II.1 - Notice and Consent. This means calling and notifying TGLN when patients meet the referral indicators for *high risk of imminent death*, and within an hour of death for non-ventilated patients.

Notification to TGLN ensures eligibility for donation can be established and donation consent decisions can be accessed in the Ontario Health Insurance Plan (OHIP) database before families of medically eligible patients are approached by TGLN about the opportunity to donate.

What are the referral indicators for high risk of imminent death?

The following are the referral indicators for ALL **ventilated** patients who meet *any* of the following criteria:

G

Grave prognosis or GCS = 3

I

Injured brain or non-recoverable injury/illness

F

Family initiated discussion of donation or withdrawal of life sustaining therapy

T

Therapy limited, de-escalation of treatment, or withdrawal of life sustaining therapy discussion planned

The following are the referral indicators for ALL **non-ventilated** patients who are at high risk for imminent death and meet *any* of the following criteria:

- Therapy limited, de-escalation of treatment, or withdrawal of life sustaining therapy discussion planned
- Planned palliation or admission to palliative care units
- Within 1 hour of death
- When the topic of donation is raised by the family or healthcare team

Does providing information to TGLN breach any privacy laws?

No. The *Trillium Gift of Life Network Act*, section 8 (19), states that TGLN may directly or indirectly collect personal health information for purposes related to donation or transplantation. This law takes precedence over other privacy and health information laws. This includes collection of family contact information in addition to clinically relevant information required to make a determination of eligibility to donate.

Is it legal for TGLN to obtain consent over the phone?

Yes. Consistent with the *Trillium Gift of Life Network Act*, telephone consent requires two witnesses to confirm the patient substitute's identity and document consent for donation. The Provincial Resource Centre at TGLN always has a second TGLN staff member available to enable telephone consent.

How does donation impact a family's grief?

Studies have repeatedly shown that families were grateful to be given the opportunity to donate. Donation provides a family with something positive in an otherwise negative life situation. It is a way for a family to honour their loved one's dying wishes to be a donor when consent decisions are known. The opportunity to help others in need of lifesaving skin transplants for burns, tissue for sight, or mobility restoring transplants is often comforting for grieving families.

To ensure families are not disappointed, it is important to contact TGLN to establish medical eligibility prior to any discussions about donation.

"My husband gave the gift of sight to two people because a nurse provided Trillium Gift of Life Network with the needed information."

Eya Donald-Greenland,
proud donor family member.

How long does the notification process (Call-Screen-Connect) take?

An evaluation of the process by healthcare professionals in designated hospitals indicated that eligibility for donation was established quickly. If not medically eligible to donate, the routine notification call for a patient is two (2) to three (3) minutes long. If the patient has potential to donate organs or tissues, the initial call *may* take 8-10 minutes.

To **reduce the time** on the phone, TGLN has created worksheets to help healthcare professionals prepare the information needed to screen the patient for eligibility to donate.

How does the notification or Call-Screen-Connect process work?

When you have a time of death to report or a patient meets the referral indicators for *high risk of imminent death*, follow these steps:

1. Prepare the *Routine Notification Worksheet* then **CALL** TGLN and answer questions (**SCREEN**) to determine if the patient has the potential to donate organs or is a tissue exclusive donor. *If there is potential for organs, the TGLN coordinator will set up a plan with the healthcare team for continued evaluation and support.*
2. If the patient is determined to be a tissue exclusive donor and the family is at the hospital, TGLN will ask you to arrange for our coordinator to speak to the family (**CONNECT**). When you arrange the call between TGLN and the family, please use a private location with a phone, if available.
3. During the time it takes to discuss tissue donation with the family, TGLN will request the body and chart remain on the unit, if possible.
4. TGLN will ask for further clinical information (outlined on the *Next Steps Worksheet*) when the family consents, *or* if the family is unavailable at the time of your initial call to TGLN.
5. The healthcare professional will be asked by a TGLN coordinator to follow the steps provided to preserve tissue integrity, such as ensuring eyelids are closed.
6. Upon completion of the consent with the family, TGLN will fax a copy of the consent form to be placed in the patient's chart.

What happens if the family is not at the hospital?

If the family is not at the hospital, and preliminary eligibility has been established, TGLN will proceed with gathering clinical information and contact the family by phone. TGLN will fax a form that directs the hospital to contact TGLN before it releases the body to ensure the opportunity to donate is not lost.



Routine Notification Worksheet (Call Screen Connect)

Trillium Gift of Life Network (TGLN)

Call TGLN at 1-877-363-8456 or 416-363-4438.

TIP: Have chart on hand for the call

After conversation with TGLN-Hospital Staff please check:

Eligible for donation
 Not eligible for donation

A call is required at the time of death:

Yes No, patient is not eligible for donation

TGLN # _____

You will be asked:

1. Telephone – Hospital – Unit – Fax number
2. Name & Designation of caller - must be RN, RPN, RN (EC), RT, or MD
3. Name of patient: _____
4. Date of Birth: Day _____ Month _____ Year _____
5. Gender : Female _____ Male _____
6. Hospital Record Number (MRN): _____
7. Ontario Health Number: _____ Version Code: _____
8. Is the patient ventilated? Yes _____ No _____ (If yes, the call will be transferred to a Coordinator to assess for organ donation potential)

Note/Chart: TGLN number #: provided at this point.

9. Date/Time of Death: Day _____ Month _____ Year _____ Time: _____ (hrs)
10. Clinical history - Use the sidebar on the right to indicate a positive history of any of the conditions listed.
11. What is the suspected cause of death? _____
12. Mechanism of Death: _____
13. Date of Entry/ Admission to hospital: Day _____ Month _____ Year _____
14. Intubation Date(if applicable): Day _____ Month _____ Year _____
15. Extubation Date(if applicable): Day _____ Month _____ Year _____

If there is potential for tissue donation, the TGLN Coordinator will be speaking to the family about donation. Please provide the patient's NOK information.

16. NOK Name: _____ Relationship: _____
 Contact #1: _____ Contact #2: _____

Document call to TGLN, the TGLN #, and donation eligibility in the patient's chart.

Note any of the following:

- HIV
- Hepatitis B
- Hepatitis C
- MRSA (current)
- VRE (current)
- C. Diff (current)
- ESBL
- CJD (Mad cow)
- Rabies
- TB
- Alzheimer's
- Parkinson's
- ALS
- MS
- Leukemia
- Lymphoma
- Documented Sepsis
- Isolation precautions

Note: Eligibility is assessed on a case-by-case basis.



Routine Notification Worksheet (Call Screen Connect)

Trillium Gift of Life Network (TGLN)

When a patient is ventilated the Coordinator will ask:

1. What is the patient’s admission history (including any cardiac arrests, defibrillation, CPR, and current cooling protocol)?
2. Was there a brain injury during this admission such as a stroke, cardiac or respiratory arrest?
 - If yes to the above, the coordinator will ask for information about the neurological assessment findings including:

- | | |
|-------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Pupil response to light • Cough and gag reflexes • Response to pain | <ul style="list-style-type: none"> • Ventilator settings and mode • Patient’s respiratory efforts • Use of sedation/paralytics |
|-------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|

3. Is there a plan to discuss withdrawal of life sustaining therapy, limit therapy, de-escalation of care or DNR status?
4. What is the patient’s past medical history, including history of surgeries and cancers?
5. Is the family present and are they aware of the patient’s prognosis?
6. What are the patient’s current vital signs? (Lab values may be requested as well)
7. What is the hospital plan of care?

At the end of the call: The Coordinator will advise the healthcare professional of the patient’s eligibility for organ and tissue donation and develop a plan with the healthcare team to ensure the donation opportunity is preserved.

≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈ ≈

When appropriate, TGLN will ask to speak with the family over the phone.
Refer to the TGLN Coordinators as Coordinators who work with the hospital.
This helps families feel the patient’s care is coordinated.

Language to connect families with TGLN

Possibility 1- Guide Family through End-of-Life

When families ask: “What do we do now?”

“One of the next steps for families is to speak with a Coordinator to help with some of the decisions that you will be making. We can arrange that now or in a little while, before you leave the hospital”.

or

Possibility 2 - Normalizing

“As part of end-of-life care and to help with some of the decisions that need to be made, we arrange for families to speak with a Coordinator on the phone. We can do that in a few minutes or before you leave the hospital”.

When the family asks about organ and tissue donation:

“We’ll be calling Trillium Gift of Life Network to determine if there is the opportunity to donate. They will be available to speak with you about donation”.



Next Steps Worksheet

Trillium Gift of Life Network
 Provide information to the Provincial Resource Centre
 1-877-363-8456 or 416-363-4438

TGLN # _____

To further assess donation potential, The Provincial Resource Centre Coordinator will ask you some or all of the following:

1. Admission History/Course of Events
2. Cancer History
3. Past Medical History
4. List patient medications:

5. Was the patient on antibiotics? Yes ____ No ____
 - a. If yes, which one(s)? _____
 - b. For how long? _____

6. Most recent WBCs (white blood cell count) and temperatures:

Date	Time	WBC

Date	Time	Temp

7. Recent Cultures:

Type	Date	Results
Blood		
Sputum		
Urine		

8. Does the patient have active sepsis? Yes ____ No ____
9. Last chest x-ray? Day _____ Month _____ Year _____
 - a. Did it indicate pneumonia/consolidation? Yes ____ No ____
10. Does the patient have Diabetes? Yes ____ No ____ If yes, Type 1 ____ or Type 2 ____

Next Steps Worksheet

Trillium Gift of Life Network
Provide information to the Provincial Resource Centre
1-877-363-8456 or 416-363-4438



TGLN # _____

Just a few more questions...

11. Name of Family Physician: _____ #: _____

12. Name of Attending/Pronouncing Physician: _____

13. Coroner's Case? Yes ___ No ___ Name of Coroner: _____

14. Autopsy Pending? Yes ___ No ___

a. In hospital ___ Patient being transferred to: _____

15. What is the patient's estimated or actual height and weight?

a. Height: _____ cm / ft

b. Weight: _____ kg / lbs

16. Did the patient receive IV fluids (N/S, D5W, Ringers, etc.) in the hour before death?

Type	Amount

17. Did the patient receive blood or blood products (FFP, albumin, etc.) in the last 48 hours before death?

Type	Amount

Thank you for your time.

Note: This form contains confidential personal information. Please retain or dispose in accordance to hospital policy.



Frequently Asked Questions for Healthcare Professionals

1. Who is eligible to donate organs at death?

- Only patients who have **sustained a nonrecoverable injury** and are **on life-sustaining therapy** (i.e. ventilator and IV medication to support hemodynamics) at the time of notification to Trillium Gift of Life Network (TGLN) may donate organs.
- Most organ donation occurs after the person has been pronounced dead by neurological criteria.
- The opportunity to donate organs after cardiac death exists when patients do not meet criteria for neurological death.
- Only 1.5% of all patient deaths are eligible to donate solid organs at death.
- The organs that may be donated for transplant include: heart, lungs, liver, kidneys, pancreas, and bowel.

2. Who is eligible to donate tissue at death?

- All patients have the *potential* to donate tissue after death.
- Tissues do not require blood flow at the time of recovery and therefore the opportunity to donate tissue is possible for most patients and families.
- Tissues that can be donated include: ocular (eyes), musculoskeletal (bones), cardiac (heart valves) and skin.
- Ocular tissue for transplantation requires recovery within 12 hours of death. Other tissues can be recovered within a 24 hour

time period if the patient has been transferred to the morgue after death.

3. What are the benefits of donation for patients and families?

- Families who donate consistently report they were 'grateful' to have the opportunity to donate and help other people.
- Donation can create a legacy of hope for donor families as it provides a sense of something positive coming from a tragic situation.
- 93% of Ontarians support donation for transplant.

4. I know organ donation saves lives, how does tissue donation help other people?

- Donated tissue restores independence and improves the quality of life of thousands of Ontarians every year.
- Eye donation restores sight after disease, injury or congenital blindness.
- Bone donation restores mobility and prevents amputation.
- Heart valves repair congenital heart defects, primarily in children.
- Skin donation provides life-saving wound covering for patients with burns.



Frequently Asked Questions for Healthcare Professionals

Trillium Gift of Life Network
Organ and Tissue Donation



5. How does the timing of a referral impact the outcome of donation?

- To provide the best possible support to families and healthcare professionals, TGLN requires notification **prior** to a family discussion by the hospital team regarding withdrawal of life sustaining therapy or testing to confirm neurological death.
- Consultation between TGLN and the healthcare team is crucial prior to the donation discussion with the family to provide the best information possible about donation potential.
- To learn if a registered donation consent decision is on file prior to approaching the family about donation, contact TGLN.

6. What is neurological death?

- Neurological death involves the irreversible loss of brain stem reflexes, such as cough, gag, pupillary response to light and response to painful stimuli.
- The capacity for consciousness has been irreversibly lost.
- The ability to breathe is no longer present (apneic) and mechanical ventilation is required.
- A known etiology capable of causing death by neurologic criteria must be established.
- To preserve the opportunity for donation, ventilation and IV medication to support hemodynamics must continue.
- The time of the first completed determination of neurological death is the legal time of death for that person. This is the time that is written on the death certificate.
- Prior to organ donation, neurological death is always diagnosed by two physicians.

7. What needs to happen before donation is discussed with the family?

- Contact TGLN to determine donation potential and learn the patient's registered donation decision on the back of their

Ontario Health Card and in the OHIP database.

- To donate organs, the patient must be on a ventilator and their heart must continue to beat; organs need to be perfused with oxygenated blood until they are recovered for transplant.
- Statistics show a joint approach involving a member of the healthcare team and a TGLN coordinator with special training on speaking to families about donation is the most successful method in offering the opportunity for donation.

8. What are some conditions that may lead to neurological death?

Many conditions may result in neurological death. Some of the most common include:

- Intracranial hemorrhage
- Cerebral ischemia
- Anoxia/hypoxia
- Traumatic brain injury
- Brain tumor
- CNS infection

9. What is donation after cardiac death (DCD)?

- Organ donation after cardiac death – or DCD- is a procedure whereby organs for transplantation are recovered following pronouncement of death based on cardio-respiratory criteria rather than neurological criteria.
- In situations of organ donation after cardiac death, the patient has sustained a **non-recoverable injury**, but **does not meet the criteria for neurological death**.
- DCD is a possibility for families **only after a consensual** decision between the healthcare team and family has been made to withdraw life sustaining therapies, but **before** the actual therapy is discontinued.
- Contact TGLN **prior** to discussion of withdrawal of life sustaining therapy with families to determine donation potential and patient's registered consent decision on file.

Frequently Asked Questions for Healthcare Professionals

Trillium Gift of Life Network
Organ and Tissue Donation



- For more information on Donation after Cardiac Death please contact TGLN and request the “*Donation After Cardiac Death, Frequently Asked Questions for Healthcare Professionals.*”

10. When do I call TGLN?

Call when there is a plan for mechanically ventilated patients to:

- Perform testing to confirm neurological death.

OR

- Set a planned time with the family for withdrawal of life sustaining therapy (extubation or removing ventilator or IV medication supporting hemodynamics).

Also:

- As per hospital policy and/or established Clinical Triggers.
- Prior to offering the opportunity for donation to families.
- When the patient/family is requesting information about organ and tissue donation.

11. How does Coroner involvement impact the donation process?

- In coroner’s cases, permission from the Coroner to recover organs and tissues is required. The Coroner’s office works closely with TGLN to honour the decision of patients and their families to donate.
- If the Coroner requests an autopsy, organ and tissue recovery occurs before the autopsy is performed.

12. What is the process for organ donation following neurological death?

- Identification of the patient as a potential donor and contacting TGLN to establish initial medical suitability are the first steps of the donation process.
- In cases of neurological death, a thorough neurological examination (testing of all brainstem reflexes, including an apnea test) is conducted by a physician to confirm

neurological death. A second neurological examination must be completed by a different physician prior to proceeding with organ donation.

- After death is pronounced, the family is provided with a time of death.
- The family is offered the opportunity of donation after they have had time to understand the death of their loved one has occurred.
- In situations where families are asking about donation prior to an expected death, the conversation about donation may occur before neurological testing. A TGLN coordinator should be involved in this discussion.
- The patient must remain on a ventilator and continue to receive support to maintain hemodynamic stability.
- Thorough testing, such as frequent blood work, chest x-rays, an echocardiogram and bronchoscopy, may be required to further determine which organs are suitable to donate.
- Infectious disease testing is performed by TGLN.
- When organ donation occurs after neurological death, the family will have the opportunity to say goodbye to their loved one while the body remains ventilated prior to the transfer of the patient to the operating room for organ recovery.
- When organ donation occurs after cardiac death, the family may be present during the withdrawal of life sustaining therapy.
- Surgical recovery of organs is done in the operating room. The procedure can take up to 4-6 hours. Once the organs no longer need to be perfused and oxygenated, the ventilator is turned off.
- After organ recovery, the care of the body is completed in the OR. If the family has requested to view the body following recovery, arrangements to find an appropriate location to facilitate this request will be made.

Frequently Asked Questions for Healthcare Professionals

Trillium Gift of Life Network
Organ and Tissue Donation



- Upon request, TGLN will contact the family when recovery is complete. A letter will be sent to the family to thank them for their gift.

13. What is the process for tissue donation?

Notify TGLN:

- Within one hour of the patient's death.
- As per hospital policy and/or established Clinical Triggers.
- When the patient/family is requesting information about organ and tissue donation.
- During the initial call, TGLN will collect demographic information and ask baseline questions to determine if there is the opportunity to donate tissue. A TGLN number will be provided to document in the medical chart.
- If the patient's preliminary eligibility to donate tissues has been established, a TGLN coordinator who is a specialist in the area of both donation and speaking with families, will arrange with the healthcare provider to speak to the family by phone while they are at the hospital.
- If the family is not at the hospital the healthcare provider will be asked to provide contact information to TGLN for follow-up with the family.
- Blood samples as well as eye care instructions may be requested by TGLN
- TGLN will collect further information about the patient's current admission and past medical history prior to contacting the families in situations where the family is not at the hospital.
- As directed by TGLN, the body is then transferred to the morgue while the recovery is organized (eyes *may* be recovered on the unit where death occurred).

- An operating room is required for the recovery of skin, bone and cardiac tissue. Recovery staff and OR will be arranged by TGLN.

- Upon request, TGLN will contact family when recovery is complete.
- TGLN (or the Eye Bank of Canada if appropriate) will send a letter to the family to thank them for the donation and to inform them of the donation outcome.

14. Does communication occur between the donor families and recipients?

- The identity of both donor families and recipients are protected through the *Trillium Gift of Life Network Act* and kept anonymous and confidential by TGLN.
- Donor families and recipients are encouraged to write and exchange anonymous letters to one another. These letters are screened for any identifying information and are forwarded through TGLN.
- Many donor families and recipients are comforted by the correspondence they receive.

15. Where can I find additional information related to organ and tissue donation?

- For clinical questions about organ and tissue donation, or to refer a potential donor; contact the Provincial Resource Centre (available 24/7) at 416-363-4438 or toll-free at 1-877-363-8456.
- TGLN's website provides a complete section for healthcare professionals, including an on-line manual for "*Routine Notification in Ontario Hospitals*". Please visit us at www.giftoflife.on.ca
- Pamphlets and education materials are also available from TGLN.



Ontario

Trillium Gift of Life Network