Resurrected Bodies: Individual Experiences and Collective Expressions of Organ Transplant in North America

by

Arlene L. Macdonald

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Arlene L. Macdonald, Centre for the Study of Religion, University of Toronto

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Abstract:
The dissertation is an ethnographic study of religion as conceived and experienced by organ transplant recipients. It is also a cultural study of North America’s collective expressions of transplant as found in Christian journals, popular media, advocacy literature and public policy statements. The study finds evidence that religious metaphors and directives, cosmological figures and theological arguments, rituals, scriptures and places of worship are actively, vociferously, and consciously engaged with organ transplant discourse and with the experience of giving or receiving organs.

While the transplant recipients under study cannot be considered representative (being largely advocates for transplant and almost exclusively of Christian background or affiliation), this group was articulate about the ways their new organ invoked the sacred: they described new metaphysical understandings, they spoke of a closer relationship with God, the universe and other human beings, they divulged inexplicable incidents and mystical states of being, they articulated a complex set of ethical prescripts. “Thinking how many times you should have been dead and you’re still here” was for many an imperative to “start to find out why.”

I argue that these spiritual seekers traverse a 21st century terrain shaped by the practices and discourses of what Foucault termed “biopower”. The private and public production of sanctified donors and ‘redeemed’ recipients is inextricably bound to the desires of transplant professionals and government officials, and cannot hope to escape the very real commodification of the body that transplant represents. This seeming paradox of ‘the sacred in the secular’ does not make transplant’s religious constructions inauthentic or irrelevant. Religion remains an active and inventive register for the recording of potent bodily experiences of illness, loss and conditional regeneration. Further, the religious activity around transplant affords a window on emerging rites, on contemporary understandings of death and immortality, and on new conversations about miracles and morality. Circuits of biotechnology are not immune to religious influence and inflection – but, simultaneously, contemporary religious meanings, practices and experiences are indelibly shaped by our newfound ability to transplant organs.
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They say it takes a village to raise a child and I suspect the same might be said of a dissertation. This thesis has been constructed on a scaffolding of family and friends -- too numerous to name, but all vital. Their love, labour, wisdom, humour and talent are its girders. My mother, Reta Minaker, provided daily reinforcement; Lorraine VanderHoef has been a mainstay since day one.

I am deeply indebted to the organ transplant recipients (realized and waiting) – and to the donors, family members and transplant professionals – who gave their time, their stories and their companionship to me on so many occasions. What I have learned from their narratives cannot entirely be captured in the dissertation.

I have also learned from the illness narratives of my family members, particularly those of John Reme and Robert Macdonald.

The dissertation is dedicated to my father, Robert Macdonald, and to my son, Curtis Reme.
“It didn’t work right away,” said Adele Gallant of her fourth kidney transplant. Her first three transplants had been unmitigated failures; the last rejection, nine years previous, had been life threatening. Emotionally and physically spent from years on dialysis, she had elected (against the wishes of her family) to try another transplant. But, in the hospital recovering from the surgery, things once again looked grim.

I have a very strong faith and I just prayed and prayed. And I have so many people praying for me. One lady, she knew some convent or nuns or something halfway across the world – I forget where it was – and she told them. She even wrote them or phoned them or whatever to say repeated prayers for me. They were praying for me. My boyfriend at the time, I’m still friends with him now, he told everybody to pray for me. I had so many people praying for me…. Prayer came into play because, this sounds farfetched, but this is what happened:

This one night I got a bit of a pain in my side where my kidney was. And it’s raining, and it was thundery and there was lightning. And I got up out of my bed. I looked out of the window and I looked up at the lightning and thunder and I said to God, “Oh, please God, please make this kidney work, please do that.” I just prayed very hard. And then I get another pain in my right side and went to the washroom to see if that would help and I started peeing.

And it was like, “Oh my God!” This was unbelievable. I screamed for the nurse, of course, and she came running to me and I’m sitting on the toilet and she said, “What’s wrong, Adele?”

I said, “I peed a little bit.”

“Oh, don’t get your hopes up, don’t get your hopes up. Only just a little bit. Don’t get your hopes up.”

“I peed, I peed!”

“Oh, okay.”

“I haven’t peed for 25 years [inaudible].”

“Oh, okay.

But I just know, I know. Next morning it started working, started working so… That morning too there was a beautiful rainbow. I call my kidney Rainbow because it means rebirth and after a storm there’s always a rainbow. So yeah, it was very touching to me,
that moment in my life. Because you kind of almost give up and then the clouds part and all of a sudden I started going to the bathroom

Organ transplant gives a uniquely modern cast to perennial questions of body and identity, illness and health, death and survival. But modern does not equate to secular. Narratives of organ transplant, professional, individual and collective, are not removed from religious influence and inflection despite the technology’s disruption of traditional definitions of death, body, person and community. In fact, transplant technology can resurrect a spiritual body, but the very categories of body, self, other and indeed religion become complicated and contested in its wake.

From its inception in the 1950’s, organ transplant has expanded exponentially. Medical centres performing transplants have proliferated; the number of organs transplanted has climbed dramatically; types of organs and tissues transplanted, singularly and in combination, have diversified; the pool of potential donors, both cadaveric and living, continually widens through the introduction of new procurement protocols and technologies; government funding, infrastructure and advocacy has increased. Yet as the field of transplantation grows, so too does the demand for organs.

Solid human organs can be harvested (the preferred term in social science literature), procured (the preferred term in medical literature) or donated (the preferred term in advocacy literature) from a limited population. Solid human organs are distinguished from tissue transplants, which include bone marrow, heart valves, corneas, and skin. Kidneys, and increasingly segments of the liver (and more rarely lung segments, partial pancreas or small bowel segments), may be sought from living donors emotionally or genetically related to the recipient. Living donors must be a suitable
match to the recipient in tissue and blood type as well as size, and must be considered fit, medically and psychologically, to donate. Approximately 35% of all organs transplanted in Canada are obtained from this source.

The remaining 65% of transplanted organs (kidneys, livers, hearts, lungs, pancreas, small bowel) are obtained from deceased donors who have suffered some sort of brain trauma and are pronounced brain-dead. This particular definition of death, proposed by the medical profession in the late 1960s and subsequently recognized in law throughout North America, has been crucial to the advance of transplantation. A neurological exam confirms that the patient shows complete and irreversible cessation of all brain activity (hence the designation ‘brain-dead’), yet artificial respiration and mechanical support ensure that the patient’s heart pumps and that his or her organs are continually supplied with oxygenated blood. The patient is dead, according to the newer criteria for death, yet the organs maintain a sort of vitality via the assists of technology. It is this ‘life’ in the organs that makes them suitable for transplantation. The organs of someone pronounced dead by the more traditional definition of death (cessation of heart beat) would be damaged, traumatized by lack of blood flow, and could not be transplanted. In addition, not all organs from would-be donors, even among the brain-dead, are suitable for transplant. Donor disqualification on the grounds of organ damage, age, communicable disease and lifestyle (because it carries the implication of disease even if doctors find no demonstrable evidence of it) is not uncommon.

Organ donors, then, must meet very specialized criteria and qualifications. Simply signing an organ donor card will not make one an organ donor on the occasion of their death. Further, all organ donors, living and deceased, must formally consent to be
donors either directly and/or through their next of kin. Canadian law insists on voluntary donation and forbids any sort of payment for organs. The number of consenting donors, culled from the limited pool of available donors, has not kept pace with the number of people suffering from end-stage organ diseases who are considered good candidates for organ replacement therapies. This situation is commonly referred to as the ‘organ shortage’.

The shortage has generated lists of people suffering or dying from organ failure, waiting to receive a donated organ. Canadian statistics for 2007 show 2,252 transplants performed, and more than 4,000 persons waiting for organs, generally in a deteriorating state of health. Of those waiting, 198 died in 2007 before an organ became available. In Canada, waiting lists and organ allocation are managed provincially by uneasy alliances of government officials and medical professionals. The shortage itself is addressed by a complex array of public policies, medical protocols, media campaigns and donor and recipient initiatives. Ironically, the industry’s tremendous growth has exacerbated rather than eliminated ‘organ shortages’ because the advances in transplant technology mean transplant is a preferred treatment for an ever-increasing number of candidates and an ever-expanding range of diseases (Hogle 1999, 4; Sharp 2006, 18).

In the decades since the 1950s what has grown as thick and diverse as the transplant industry, as ubiquitous and prominent as the waiting lists, is a discourse about organs. Transplant discourse emanates from the myriad cultural centres that the transplanted body disrupts: law, government, medicine, ethics, social science, and religion. This discourse is not merely commentary on transplant, but has a force and reality distinct from its contents. In the *History of Sexuality* Foucault traces the myriad
discourses of sex and the inextricable connections between discourse, truth and power. “Sex”, he writes, “was driven out of hiding and constrained to lead a discursive existence” (1976, 30). Transplant discourse has likewise driven organs into public vision and lexicon; it has done so as surely as transplant technology has lifted them from concealment in the body.

The exchange of ideas, images, stories, slogans, appeals and arguments about organs, disseminated from many centres both popular and official, has bred a public familiarity with this once exotic form of medicine and generated another kind of ‘organ trade’ in sermons about our bodies and our selves. Transplant discourse engenders a social imaginary that configures bodies, individuals and societies, considers the generation and continuity of life, scripts gender, ethnicity, and citizenship, partitions health and illness. “T.A.L.K.!!!” shouts one advocacy poster, “Tell All Living Kin about organ donation!” But the appetite for organs is not limited to the chronically ill or dying recipients who receive them and the transplant professionals who procure them. Organs, for scientists and medical researchers, are keys that unlock the body’s immune system and are potentially the holy grail of therapeutic cloning. Organs, for law and policy makers, are the frontispiece of life-saving public health care and the infrastructure of a corporeal republic. For ethicists and philosophers, organs are a litmus test of human limits, social relations, and universal values such as justice and compassion. High school courses introduce the topic of ethics through a study of organ transplant. Bioethics journals overflow with debates about brain death, organ procurement and equitable allocation. For social scientists, including anthropologists, organs are magnifying glasses that sharpen and enlarge the bodies central to their fields: the existential lived body-self,
the social, representational body, and the body politic. They have produced a smorgasbord of considerations about the meaning, language, ethics, employment and experience of organs. This study likewise uses organs and their exchange to examine contemporary bodies, but it insists that the spiritual body is an important, if often overlooked, figure in transplant discourse and experience.

In the limited social scientific exploration of the relationship between religion and organ transplant the primary concern is Christianity’s influence on western constructions of the body. Drawing primarily on medieval Christian doctrine and ritual, occasionally on the works of the Church fathers, commentators focus on two Christian tenets. Heavily weighted is the Christian notion of an embodied soul, the idea that one’s body is a vital and inseparable component of one’s person, or soul. In Christian theology the incarnation of Christ bears witness to the centrality of the body in life, and his bodily resurrection points to the continuing importance of the body in the everlasting life of the soul. Considered equally important to Western notions of the body are Christian injunctions about the sanctity of the body and the conflicted Christian history regarding bodily integrity and bodily partition.

The academic mappings of the subtle Christian contours of the contemporary body are illuminative, but for the most part the social scientific literature assumes that Christianity remains a backdrop to transplant issues and attitudes -- a powerful religious heritage, but hardly an active force in the secular society we have become. The focus on Christian antiquity insinuates that living Christian belief and practice is far less influential, at least on the majority of the populace, than deeply buried, “unconscious”
cultural strata. Assertions that religious authority over the body is giving, or has given, way to scientific understandings further underscores a rubric of secularization. “The Catholic Church decided over 30 years ago that the definition of death – unlike the definition of life – should be left up to the doctors”, charges Scheper-Hughes (2000, 195). Even Lock’s (2002) careful examination of the influence of Buddhist and Shinto beliefs on Japanese resistance to brain death and organ transplant suggests that while organ transplant in Japan may be fraught with religious tension, religion in the western world (where, as she demonstrates, the altered definition of death and the technology of transplant have been readily accepted) has only a nominal or vestigial part to play in the secular saga of organ transplant in North America.

Specific links between Christianity and current transplant discourse are occasionally noted, but almost (William LaFleur 2002 is a notable exception) never explored in any depth. Sharp notes that altruism (which she claims “the most significant aspect of transplant ideology”) is a “loosely defined, Judeo-Christian-based ethic” (1995, 364). Linda Hogle (1999) remarks perceptively that the Christian ritual of the Eucharist inscribes the body as “both locus and instrument for redemption, a theme that recurs in organ transplantation” (30), and she draws an interesting argument about the multiple kinds of redemption transplant performs (190-191), but doesn’t fully pursue the implications – for transplant and, perhaps just as importantly, for contemporary religion.

The social scientific argument that religion of long ago and far away (namely Christianity) has deposited deep yet unconscious layers of cultural sediment that continue to influence North American attitudes to the body, and therefore transplantation, fails to do justice to the vitality, the plurality, and the continuously evolving religiosity of
contemporary North Americans. Further, it contravenes the overwhelming evidence that religious metaphors and directives, rituals and scriptures, actors, theologies, and places of worship are actively, vociferously, and consciously engaged with organ transplant policy and discourse, and the experience of giving or receiving organs.

Scriptural reference, religious directives, and theological debate about transplant technology appear where one might expect them to – in formal sectarian resolutions, theological vision statements, religious medical codes, denominational journals and the writings of religious ethicists. Christians have been especially prolific in this kind of religious interpretation of organ transplant, but rabbinic commentary and Islamic medical codes, even fatwa, on the subject have also been produced. But this is not where religious reflection remains. The sectarian views on donation and transplant (especially when favourable) are collected and disseminated in advocacy literature, government websites regarding transplant policy, and bioethics publications. Clergy enter the transplant field via public media and public rituals. Hospital chaplains venture even closer to the exchange of organs. Transplant procurement professionals and other advocacy groups reach out to faith organizations to secure their commitment to organ donation. They extend information about transplant and donation but also lend them scripture, sermons and sample bulletin inserts to use in their pastoral efforts. Scriptural passages circulate in unlikely places: Genesis 2:21-23, the transfer of Adam’s rib to Eve, graces the preface to a clinical book on transplant (Hakim 1997); an American transplant education website sponsored by the federal Division of Transplantation responds to the query ‘how many lives are touched by donation?’ with the Talmudic response: ‘He who
saves one life, it is as if he saves the world entire’(http://www.journey.transweb.org/); bio-ethicist Robert Munson (2002) calls the heart recipient “a modern Lazarus’.

Even more predominant than literal borrowings from scripture are the allusions to religious cosmologies, religious figures, religious practices and religious beliefs that crowd advocacy campaigns, popular media, and donor and recipient narratives. The metaphor that heralds donation or receipt of an organ as conferring or receiving ‘the gift of life’ is circulated in myriad official and unofficial transplant discourses and is omnipresent in the public and private narratives of donors, recipients and transplant professionals. Such a metaphor has the imprint of the Genesis account of creation, the inference of God and mystery, Christ-like sacrifice of body and subsequent renewal. William LaFleur’s (2002) work makes clear that, “when scratched even only lightly such a phrase, even when it is passed off as secular, reveals close to its surface the notion of agape” (640). The analogy with Christ’s sacrifice is explicit in the post-modern passion play of organs presented in the movie Jesus of Montreal and implicit in a host of radio shows, newspaper articles, and medical reviews claiming organ transplant as miracle, second chance, new life, renewal, resurrection, even “the arena of the redemption of death” as the May 1987 issue of Canadian Doctor referred to it (as quoted in Houlihan, 1988, 31).

And Christ is not alone. The transplant discourse is populated with a host of angelic donors and legions of transplant demons. The gift of life metaphor as employed in popular literature affixes the persona of a modern day saint to donors and the role of grateful penitents to recipients. A multitude of website memorials portray donors as angels looking down from heaven. Their virtues are extolled in literature that borders on
hagiography. Penitents, however, simultaneously embody the relief of deliverance, the countenance of contrition and the stigma of sin. The moral ambiguity of the transplant recipient is reflected in tales of organ snatching, organ markets, and organ murders told in tabloid accounts, scholarly exposes of the third world, urban myths, contemporary novels and television dramas. In these dramas of recipient temptation transplant doctors and organ brokers frequently do the work of the devil. But in alternate narratives surgeons are champions of the Lord’s work, spreading hope and saving lives.

Christian cosmologies are referenced in the litany of appeals to heaven. ‘Don’t take your organs to heaven, heaven knows we need them here’ trumpets many a t-shirt, billboard, button and promotional brochure. A similar sentiment is inculcated in another widely disseminated poem/prayer continuously recycled in transplant related publications. ‘Don’t call this my deathbed,’ it begins. In multiple stanzas the author bids us to take all the myriad parts of his deceased body and redistribute them to persons in need. When there is nary a part remaining, “burn what is left of me and scatter the ashes to the winds to help the flowers grow”. “If you do all I have asked”, he concludes, “I will live forever” (Test, 1976).

Yet there is not always accord that heaven wants our organs here. Bewildered and alone after the death of her husband, ambivalent about her decision to donate his organs, Richard Selzer’s fictional character Hannah resents the radio preacher’s talk about resurrection of the flesh. “‘It’s a big lie,’ she said to her born again cousin Ivy Lou. ‘There is no such thing…What about Samuel Owens on your resurrection day?…They going to put him back together again when the day comes, or is it that to the recipients belong the spoils? Tell me that’”(Selzer as quoted in Verhey, 2000, 49). And medical
writer P. J. Houlihan (1988) begins her ethical treatment of organ transplant with a transplant surgeon meeting St. Peter at the pearly gates – and being unsuccessful in his supplication. “‘I am afraid’, [God] said to the man whose stature had begun to shrink, ‘that I am going to have to find another place for you transplant people. I knew it would happen sooner or later. I just cannot afford the competition’” (14).

Organ transplant is intimately bound to existential questions of body and identity, illness and health, death and survival and hence fertile ground for the production of individual religious meaning and experience. Multiple religious idioms are employed in the stories recipients, living donors and donor kin tell about their experiences of illness, transplant, death and donation. Their religious narratives are widely circulated, in popular media, advocacy literature and ethnographic accounts. But they do not only tell stories.

Surprisingly prevalent are the ritual expressions of transplant that donors, recipients, transplant professionals and government officials enact. Some are traditional death rituals with a minor modification introduced by the trajectory of transplant, such as placards at funerals that let viewers know the deceased was an organ donor. Others are marriages of conventional religious ritual and transplant initiatives, such as the establishment of the National Donor Sabbath in the United States whereby congregations elect to make organ donation the theme of their services on a Sunday in November close to the celebration of the American Thanksgiving. Others are rituals specific to organ transplant that ostensibly strive to create awareness of organ transplant and encourage donation, but also work ritually to establish the meaning of transplanted bodies, the relationship of donors to recipients, the roles appropriate to both, and the place of state,
soul and society in the exchange of organs. These ceremonies borrow liberally from religious traditions (and are often held in places of worship and led by religious officials), but they also find inspiration in a wide range of ritual gestures, both civic and popular, and are accompanied by a diverse assortment of ritual accruements – medallions, flags, jewellery, monuments, photos, websites, flowers, costumes, mascots, food and music. Donor memorials are a prominent part of this ritualization, but the rituals of transplant also include sporting events, inspirational speakers, transplant ‘birthday’ parties, highly structured donor-recipient letter exchanges, live donor recognition events, and a host of more solitary ritual acknowledgements of the power and ambiguity of organ transplants.

Why have these religious references, narratives, images and activities largely escaped the notice of organ transplant commentators? A blanket of secularization -- the theory of religion’s decline and diminishment in its collision with modernity -- covers many social scientific explorations of transplant and muffles all the religious noise around the exchange of organs. It is a comfortable blanket. Hammond (1985) argues that all social science has operated on a premise of increasing secularization; that modernization (industrialization, rationalization, bureaucratization, urbanization) is seen as the equivalent of secularization. Theories of secularization are hardly new; they were the gleeful predictions of many an Enlightenment figure convinced of the ascendancy of reason and the promise of science. Thomas McIntire (2006), a historian of religion, argues 18th century Europe’s particular intellectual and religious history installed ‘secular’ and ‘religious’ as a dichotomy, a contest of polarized opposites, that has since acted like a template for ordering discourse about historical and religious trajectories both within and without academic institutions, and far beyond Europe’s borders. But the
intensification and proliferation of secularization theory in modern scholarship can be traced to the early 20th century sociologies of Max Weber (1968, 1946). Reason may not have had the illustrious future that its Enlightenment proponents foresaw, but Weber (in keeping with a dichotomous understanding of ‘secular’ and ‘religious’) argued convincingly for the creeping triumph of rationalization.

Rationalization refers to the process of becoming more and more rational, or effectively, ‘masterful’. It encompasses conceptual mastery, the increasingly theoretical mastery of reality by means of increasingly precise and abstract concepts (science, for example, and intellectualism). It references practical mastery, the methodical attainment of a definitely given and practical end by increasingly precise calculation of adequate means (technology). And it includes proliferation of systemic arrangements, elaboration of understanding and activity into systems, codification, typologies, etc. In an evocative phrase, Weber claimed rationalization constituted ‘the disenchantment of the world’. Disenchantment was the gradual and uneven erasure of a world which “assumed that behind real things and events there is something else, distinctive and spiritual, of which real events are only the symptoms or indeed the symbols” (1968, 404) and the subjection of this vanishing world to ever more precise and invasive operations of calculation. Weber (1946) extended this basic proposition to an elaborate consideration of organized religion in the modern, rational world and found it susceptible to internal disruption, implicit devaluation and increasing alienation from the other rational spheres of the world (politics, economics, education, etc.). Modernity placed both the religions of the world and the religious world in jeopardy.
Echoes of Weber can be found in a large body of religious scholarship from the 1960s through the 1980s. The details were endlessly debated, but the central vision was repeatedly affirmed: modernity was trouncing religion. Peter Berger’s (1969) lament for the dismantling of religion’s sacred canopy – religion’s increasing inability to provide comprehensive and uncontested meaning for human collectives -- was a touchstone for many scholars. In accord with Berger they argued religion had moved from the public to the private sphere. Modern religion, they claimed, catered to individual, often psychological, needs and could be seen dissolving into syncretic, discrete concoctions of private salvation. Others spoke of dwindling religious activity or organization, and when that proved empirically difficult to defend, spoke of dwindling religious belief and commitment. And many commented on the separation of religion from other social spheres – the infamous separation of Church and State defended in the American Constitution, but more generally the differentiation of modern society into various social structures (economy, law, education, medicine) of which religion was but one. Functions formerly filled by religion were now dispersed to ever more structured and rational social spheres devoted to these ends. Consensus emerged: if not the world, then certainly North America could be claimed a secular society. Modernity had moved religion onto the fringes or into the past.

It is in the context of this ‘secular’ society that scholars of organ transplant place their arguments. Social scientific commentators generally see organ transplant as a process that exerts mastery over the body, renders its parts more and more useful, less and less meaningful. Organ transplant, many of them claim, “commodifies” the body – by this they generally mean the willful divorce of person from the body, the devaluation
of the body into a ‘thing’ like all other things, the willingness to market or exchange our most innate possessions.\textsuperscript{13} Commodification, for many social scientific observers, represents the disenchantment of the body and as such is part of the disenchantment of the world that Weber describes. As Le Breton (1994) colourfully puts it:

“For better or worse of its history, Western medicine has left the sacredness of human remains behind it; it has denied the humanity of the corpse in order to turn it into a lifeless bark, dead wood indifferent to human form... Organs are thus perceived as parts of a human structure that are detachable and mutually interchangeable. (1994, 97, 108)

Given this assumption that organ transplant is both indicative and constitutive of a secular view of the body, it is not surprising that religion is found on the fringes or in the past in the social scientific accounts of transplant. Sometimes it is limited to the distant echoes of Christian theologies of the body as in the work of Lock and Hogle. Sometimes religion surfaces as check or caution against the secularism of transplant as in Scheper-Hughes reminder of the “lively, animate and spiritualized” properties of organs (2000, 211) or Fox and Swazey’s assertion that organ transplant has brought “social, cultural and spiritual harm” in its wake (1992, 210). Religion might be found in the third world, Scheper-Hughes implies, but she is definite that ours is a “‘rational’, secular world” (2000, 203). Occasionally the explicitly religious content of transplant advocacy is noted as in Sharp’s (2001) account of donor memorial services. However, in Sharp’s work religion is not seen as a legitimate component of organ transplant, but as a “mask”, a false front for the secular work of soliciting donors and commodifying bodies.

While it may be undisputable that organ transplant technologies participate in and support a modern willingness to commodify the body, to make it both useful and alienable, the secularization correlate – that it is therefore less meaningful, less
religiously encoded, less ritually employed – is very much suspect. Indeed, religious scholars of the past twenty years have become increasingly dissatisfied with classical secularization theories. Very few scholars now believe that modernity’s embrace of rationality and science has meant the erosion or diminishment of religion – or the religious body.

In scholars’ careful explorations of what modernity has meant to religious belief, practice and influence whole new categories and understandings of religion have emerged. While Berger lamented the loss of religion’s ability to unite society under a sacred canopy of meaning, his contemporary, Thomas Luckmann (1967), attended more sympathetically to the kinds of religiosity that develop in the absence of collective and comprehensive meaning-making systems. Luckmann pointed to the individuated, syncretic, “invisible” religion that seemed emergent in North America. An emphasis on the individual religious actor and ‘unchurched’ religious activity continues to mark much scholarship on contemporary religion. The accent on the religiosity of ordinary individuals, the stress on religious experience, the willingness to legitimize this religiosity both where it converges and where it departs from orthodox religious instruction and practice is reflected in the works of Robert Orsi, David Hall (Hall 1997) and others who consider their focus to be that of ‘lived religion’.

Emphasis on religious practices outside the purview of established religious traditions also continues to be influential. Armed with functional definitions of religion, scholars seek to discover locations and activities that fulfill the functions of religion if not the conventions.14 Their search has led them to a host of activities and allegiances scattered through the official and popular cultures of contemporary North America. This
‘unchurched’ activity can be the religion of individuals (frequently coded as ‘spirituality’) or groups where it is called ‘implicit religion’ in the work of many British scholars (Bailey 1968) and explored under the rubric of ‘civil religion’ by American scholars (Bellah 1970). The consensus among scholars of contemporary religion is that religion has not been vanquished, or even diminished, by modernity. However, they add, religion has not been immune to modernity. “But of course religion changes,” Rodney Stark chides. “But change does not equate with decline!...Indeed what is needed is a body of theory to explain religious variation…in that regard, the secularization theory is as useless as a hotel elevator that only goes down” (1998, 19). Exploring the religious changes wrought by the forces of modernity, not only rationalization and industrialization, but also globalization and the increasing media saturation of our world, might very well require us to modify our definitions of religion and alter our presumptions about its features and locations.

The absence of legitimate and living religious forces and actors in the social scientific accounts of organ transplant is due to their reliance on an outmoded theory of secularization that deems that modernity, and particularly modern medicine, disenchant both the world and the body. But religious scholars open to the possibility of religion surviving in contemporary North America (perhaps even thriving albeit in new guises) argue that the body remains a central focus of religious meaning making and activity. Robbie Davis-Floyd (1992) recounts the ritualization and religious instruction embedded in medical practices surrounding modern hospitalized birth. While hers is a cautionary rather than a celebratory tale, Pamela Klassen’s (2002) ethnographic account of home birth stresses an alternate contemporary religiousity of birth, one developed out of
women’s lived and bodily experiences. Klassen’s study models the myriad ways religion can be central to the study of an intense and transformative bodily experience, and the necessary correlates to studying the construction of religion: attention to issues of gender, race, socio-economic status and power. Meredith McGuire (1988) has explored the rise of alternative healing methods among middle class North Americans and argues that the modern sick body is open to a variety of religious or semi-religious practices. Robert Orsi’s (1996) account of the (mostly female) adherents of St. Jude demonstrates the unique and innovative ways these women construct their religious lives to negotiate physical, social and emotional suffering. The body at death in contemporary North America is also featured in religious scholarship. Steven Prothero (1997) argues that cremation was not, as contemporaneous and academic accounts assert, a secular erosion of religious practices of burial, but a decidedly religious employment of the body at death, one that nevertheless incorporated modern concerns about hygiene and utility. Cremation may have been less Christian than burial, Prothero allows, but it was certainly not less religious.

Religion scholars Ann Mongoven (2003), Cheryl Sanders (1995), and William LaFleur (2002) have engaged the transplant body and their articles, to which I will return, reflect some of the nuances of modern religion and the complexity of contemporary religious bodies. However, the vast majority of scholarship on organ transplant, while it makes sophisticated use of the burgeoning literature on the body in the humanities and social sciences, is unwilling to consider the seeming paradox of ‘the sacred in the secular’ -- the religiosity of organs, the sacrality of their exchange and the sanctified bodies they construct despite the very real commodification of the body that transplant represents and
the very secularized world of transplant medicine within which the exchange is orchestrated.

Religion is far more prominently featured in bioethical treatments of organ transplant, but these accounts are no more successful than the social science literature in capturing the flexible boundaries of contemporary religion and the generative religious body at the centre of transplant. A list of various faith traditions and their stance toward organ transplant is the most common presentation of religion in bioethical accounts. Such a presentation reduces ‘religion’ to the world’s recognized faith traditions, ‘religious actors’ to the official spokespersons of these traditions, and ‘religious belief’ to moral injunctions. The concerns of contemporary religious scholars with the lived religiosity of ordinary individuals are entirely effaced in the selective attention to official religious proscriptions. From the bioethical accounts we may know better what orthodox Anglicans or Jews ought to believe about transplant, but we are no closer to understanding what those same Anglicans or Jews actually believe, and certainly no closer to understanding what they do. The disembodied voices of the world religions speaking in the bioethical literature on transplant entirely displace the body as a source of religious meaning and experience.

The delineation of particular faiths not only discriminates against less popular or less acknowledged faith traditions (traditions such as Sikhism, Baha’i, Zoroastrianism are regularly excluded from bioethical consideration as are indigenous traditions, emergent traditions, and syncretic traditions such as Santeria), it also ensures that any sort of religiosity that cannot be contained by the construct of a faith tradition will automatically be excluded from consideration. It should also be noted that although major world
traditions are included in most bioethical reviews of religion and transplant, Christianity is given predominant attention. Christian sects are often examined individually, with Roman Catholics separated from Protestants, Fundamentalists and Evangelicals remarked upon, special attention given to Christian Scientists, Mormons and Jehovah Witness, Eastern Orthodox distinguished from other sects. Almost never is this kind of scrutiny given to non-Christian traditions. Islam, Hinduism, Judaism are treated as monolithic faiths. The Chinese religions of Confucianism, Taoism and Buddhism are often lumped together. The variations of these faiths as they are practiced in diverse parts of the globe are rarely remarked upon. 16

Surveys of faith traditions and organ transplant, particularly those employed in advocacy literature to correct “the mistaken belief that there are religious constraints to organ and tissue donation”, conclude that “all major religions do support organ donation” (Organ Donation Ontario, 1998). Religious resistance, where found, sometimes results in a denigration of the tradition to the status of ‘folk belief’. More careful bioethical examinations tend to note possible religious grounds for objecting to brain death, organ donation or transplant, but ultimately decide that “no major religious or cultural group provides outright opposition to organ transplantation…none offers formal objection to it” (Veatch, 2000, 19). Some commentators resolve that religious traditions can offer no clear argument for or against transplant; ancient formulations of human nature and responsibility are not equipped to respond to modern medical technologies. But the general trend has been to construe (legitimate) religion as favourable to organ donation and transplant.
Religion in the study of organ transplant has been absent, ancient or abridged. This study asserts that there is overwhelming evidence for the prominent place of religion in the lived experience of transplant recipients and donors, in the public policy and professional activities of transplant officials, and in the collective expressions of the transplant discourse in North America. It undertakes both a close examination of this evidence, and a careful analysis of the nature of contemporary religion.

What has surfaced might profitably be called a religion of organs. Transplant scholar Linda Hogle (1999) disagrees with the oft-stated laments about the impropriety of intercorporeal exchanges, the deleterious effects on personhood, and the presumed fragmentation of the body in modernity. Hogle declares such approaches “abstract generalizations that fall apart upon examination” (23). She argues that “bodily boundaries have always been moveable” and her approach explores the cultural processes that have allowed solid body organs to become a source of and site for healing and the cultural by-products that have accompanied this retooling (20). Her claim is that organs have become “therapeutic tools” – “instruments and technological artefacts that are both culture bearing and profit bearing” (4). To the question ‘who owns organs?’ which preoccupies so much of the bioethical, philosophical, legal and social scientific writing on transplant, Hogle is able to add another question: what are organs? Her answer, ‘therapeutic tools’, is a productive one that allows many insights into the contemporary body and the material and cultural practices that surround it. But it is not the only answer. Organs, as testified by many narratives and diverse cultural imagery and practices, are sacred objects. Considering organs religious artefacts is equally as
appropriate, and affords equally as many insights into contemporary cultural practices and modern constructions of the body, as claiming them therapeutic tools.

Inescapable in the field of religious studies is an encounter with the sacred and the profane, the overarching dichotomy that informs much of the discipline’s literature including the works of renowned scholars such as Emile Durkheim, Rudolph Otto, Max Weber and Mircea Eliade. The terms are powerful. Scholars use the dichotomy of sacred and profane to establish definitions of religion, locate religion’s origins, elaborate its functions, and describe its historical manifestations. And they are elusive; definitional debates abound. Frequently the sacred is defined by what it is not: profane. The sacred is radically different than the everyday, the ordinary, the mundane or common, the trivial, the routine, the insignificant or senseless. But more than a few scholars have attempted to unravel the dimensions of the sacred itself. The sacred, scholars have argued, engages ultimate reality, is saturated with being, gives meaning and orientation, inspires awe and fear. For some scholars the power and mystery of the sacred remains distant and wholly other. But Eliade (1958) argues for the paradoxical nature of the sacred: we can only know it through its appearance in the profane.

The sacred is always manifested through some thing; the fact that this something…may be some object close at hand, or something as large as the world itself, a divine figure, a symbol, a moral law or even an idea, does not matter. The dialectic works in the same way: the sacred expresses itself through something other than itself; it appears in things, myths or symbols, but never wholly or directly (26)

The breakthrough of the sacred into the profane Eliade terms a “hierophany” and he argues that all manner of objects have served as hierophanies. The physical characteristics of the sacred object may intimate qualities of the sacred (stones endure,
they are invulnerable, beyond change) but there is no a priori material attribute the sacred is predisposed to. “A thing becomes sacred insofar as it embodies (that is reveals) something other than itself” (13). Hierophanies have their own sacred histories, Eliade argues, arising in specific times and places, venerated by particular groups or cultures, limited to local purpose or attaining world-wide significance in accordance with their revelatory abilities, sometimes enduring, sometimes fading away.

In contradistinction to Eliade, Johnathan Z. Smith (1978) has argued that ‘sacred’ myth, ritual and space need not always deal with the infinite, the cosmic and the primordial. The general insistence on such a view of the sacred in religious studies has resulted in a portrait of religious peoples, especially primitive peoples, as atemporal, illogical, ‘not like us’ and therefore not human. Abandoning grand narratives of the sacred that stress congruency and conformity, Smith probes the ways that myth, ritual and sacred objects arise from, respond to and think about the incongruous: the juxtaposition between expectation and actuality, between social understandings and social realities. He notes that such juxtapositions “structurally resemble that sudden breakthrough which scholars of religion have termed an epiphany or hierophany” (302). Smith is more interested in the application of myth and ritual to particular social and experiential disjunctions, than he is in sacred trajectories.

I lean on both Eliade’s understanding of the sacred as transmutable and eminently material and Smith’s understanding of the sacred as a strategy and an application when I assert that hearts and lungs, livers and kidneys function as hierophanies in contemporary North American society. However revered (or denigrated) the body has been in religious traditions, organs begin a new sacred history with the advent of transplant technology. It
is precisely their evacuation from the body that illuminates the sacred and brings the profane more closely into view. The transplant discourse abounds with appeals to the sacredness of organs. But this sacred history is complex; it both enjoins and cautions the technology that called it into being. Indeed, the sacrality of organs is central to the politics of transplant. Organs are posited as the opposite of profane objects – and it is this meaning of sacred that commentators employ when they argue that organs are unlike other commodities, priceless, a gift, outside the realm of purchase, and for some, outside the realm of exchange entirely. But sacred objects are also considered powerful, animate in mysterious ways, capable of exerting force, carrying associations, causing transformation.

It is primarily the generative power of sacred organs that this study tracks. The popular reference to organs as sites or agents of miracles is not merely happenstance or hyperbole. Individual recipients, donors and donor kin frequently claim that organs and their exchange can illuminate religious truths or offer avenues to pursue religious ideals. Many of my respondents insisted that transplanted organs re-engage, sometimes rework, eschatology, ontology or theodicy. Some respondents claimed that their transplant marked their entrée into, or their return to, a religious faith tradition. But there is no doubt that sudden death or chronic illness or the uncertain outcome of transplant can challenge faith; the sacred carries an ambiguous charge. Even those recipients who were loath to attribute traditional religious meanings or import to their new organ had to grapple with the power of this object, the transformations it is capable of engendering, the associations it carries. Ritual activity and carefully constructed systems of meaning were commonly employed both to acknowledge and to contain the power of the sacred organ.
The raison d’etre of these sacred objects is to heal. But religious healing concerns more than physiological cure. It concerns body and person, flesh and spirit. Frequently religious healing reaches beyond the boundaries of the immediate individual body to address the communal body and the ancestral body. While the most obvious concern for the professional and popular literature on transplant is the renewal of the physical body through the modality of organ exchange, transplant discourse also engages a conception of healing that is most accurately called religious. It is through organs that recipient minds and hearts, as well as bodies, are seen as restored or transformed. It is through organs that donors are immortalized and “legacies of health” created.\textsuperscript{17} The adoption of organs generates new kinship lineages. And the exchange and celebration of organs both delimits the boundaries of community and binds its intercorporeal members.

To call organs sacred objects and to look for spiritual as well as bodily healing in their exchange is not an endorsement of transplant, nor does it place the technology beyond critique. Although many transplant advocates use the religion of organs to do precisely this, scholars of religion need not be adherents in order to recognize and engage the beliefs and practices of the people they study. Ideally, academic studies of religious healing use the lens of religion to ask questions, but their questions are not limited to investigations of demonstrability, efficaciousness or ‘truth’. Instead, scholars ask how religious healing constructs and construes the bodies, persons and communities it treats. They ask what social and ritual function the healing performs, and what beliefs, practices and structures it leaves in its wake. These things can be critiqued – but only after they have been uncovered.\textsuperscript{18}
To assert, as Lesley Sharp (2001) does, that organ donor memorials use “green” metaphors of renewal, rebirth, and reconstruction to mask the individuality of the donor and massage the public acceptance of organ donation is to risk missing whatever generative functions these rituals may serve. Presumably ritual organizers (transplant procurement officials and others) believe they are performing something other than a surreptitious grab for organs. And almost certainly the hundreds of donor families Sharp finds repeatedly participating in these events must experience some genuine ritual accomplishment. One possible outcome of these ceremonies may be the masking of donor individuality and the silencing of critical voices, but without a sympathetic engagement with the real religious aims of such services one will never be able to assess the constructive and imaginative responses such rituals engender. Donor kin, transplant recipients and procurement personnel stereotyped as dupes of the religion of organs will afford no more insight into the motivations, concerns, and reality constructions of transplant participants than the discernment afforded by two-dimensional portraits of devotees brainwashed by cults, fundamentalists hoodwinked by televangelists, and natives bound by superstition. Assuredly, in all of these examples, relations of power are critical – but also complex.

Sharp (2006) sees the proliferation of “green” and “recycling” imagery as manipulative – such metaphors depersonalize the donor and mask the “darker reality” of tragic deaths. “The power of recycling imagery lies in its ability to focus our attention on the idea that death can beget life” (95). In Sharp’s estimation, “power” inheres in the ability to divert attention and obscure realities. But organ transplant rendered in images of caterpillars metamorphosing, leaves sprouting, and flowers blooming seems equally a
promulgation of a generative power: power over life, power “to ensure, sustain, and multiply life” (Foucault 1976, 138).

According to Foucault (1976), the “power to make live” (“biopower” in his terminology) charts its proliferation and ascendancy from the 18th century. The sovereign “right to death” is relinquished in favour of a “power whose highest function was perhaps no longer to kill, but to invest life through and through” (139). This novel force of propulsion, this “administration of life,” proceeds through both the disciplines of the body and the regulation of populations. Medicine, with its commitment to “make live,” with its applicability to both bodies and populations, is a central application and extension of the mechanisms, techniques and technologies of this new power-knowledge (2003, 252). Death continues, of course, but the exigencies of life are increasingly “brought into the realm of explicit calculations” (1976, 143). “It was the taking charge of life, more than the threat of death, that gave power its access even to the body,” Foucault writes (1976, 143).

Masks and evasions are not the order of biopower. Paul Rabinow and Nicolas Rose (2006), extending Foucault’s formulations to contemporary biotechnologies, argue that biopower is not a subterfuge inflicted by the state and its authorities, but an extensive “economy of vitality” carried by a plurality of actors:

not least among them being the patients, their families, their communities themselves, not to mention the transnational pharmaceutical companies, biotech industry, massively funded science faculties, ethics commissions, regulatory agencies – and the vociferous social critics of bioscience and genomics themselves (Rabinow & Rose, 2003, xxx)

This economy rests on “truth discourses about the ‘vital’ character of human beings,” “an array of authorities considered competent to speak that truth,” “strategies for intervention
upon collective existences in the name of life and health” and “modes of subjectification, in which individuals work on themselves in the name of individual or collective life or health” (Rabinow & Rose, 2006, 195).

The organ recipients and donor kin that flock to transplant ceremonies are biopower’s subjects, dedicated to the promulgation and optimization of life. And the transplant professionals that mount such ceremonies are power’s authorities, speaking the “truth” of the generative, ‘vital’ organs at the heart of the transaction. For those situated within the economy of vitality, transplant’s disingenuous metaphors and nefarious goings-on seem peripheral to the knowledge collection and problematization at hand. I have watched transplant surgeons read from Sharp’s work with pained expressions and listened to bioethicists cheerfully denounce anthropologist Nancy Scheper-Hughes as “crazy.” They do not find it inherently troubling that power has access even to the body, for what animates organ transplant is “the politics of life itself: the growing capacities to manage, engineer, reshape, modulate the very vital capacities of human beings as living creatures” (Rose 2007, 3).

Scholars debate whether biopower is a dark or benign force, an unstable or a hegemonic presence. It is, however, this power, the “administration of life,” that holds the key to the religious impulses and expressions embedded in organ transplant. Rose (2007) contends that biopower proffers the hesitant potential basis of a new ontology. In this sense, our bodies have become ourselves, become central to our expectations, hopes, our individual and collective identities, and our biological responsibilities in this emergent form of life. (105)

Recasting Foucault’s discussion of pastoral power, Rose emphasizes the “somatic ethic” that develops around the new responsibilities, choices and hopes engendered by
biotechnologies. By claiming organs as sacred objects in an economy of vitality, I hope to elucidate the particular somatic ethic embedded in organ exchange, consider the complicated solace that it offers recipients, and examine more closely the ways the religion of organs both extends and eludes “the will to life”.

Claiming organs as sacred objects also allows a whole range of transplant discourse and practice to be examined, rather than ignored. “Boundaries of human and nonhuman, living and dead, natural and technological are managed,” Hogle writes, and hers is a careful study of some of the cultural constructs and material practices that have prepped the body for transplant. But religious experience is not among them. The only hint in the social scientific literature of religious or spiritual constructs actively managing body boundaries is the rather overworked notion of ‘incorporation fantasies’: transplant recipients haunted by an organ that retains the sensibility of the donor. None of my respondents related an incorporation fantasy. But they did speak of voices, visions, visitations, premonitions, prayers, talismans, hallowed places and sacred bonds that populate and grow out of their experiences of illness and transplant. And they generously allowed me to observe the ceremonies, competitions, memorials, marches, parties, private rites, proselytizing, revered donor-recipient letter exchanges, hymns, chants, and testimonials that reflect and form their understanding of the transplant body. Religion has been a powerful force in the construction of the body, notes many a transplant scholar as they point to early Christian struggles with flesh and spirit. What this study wants to make clear is that religion – both lived religions and implicit religions – remains an active, inventive and influential register for the management and contestation of
contemporary body boundaries and for the recording of potent bodily experiences of illness, loss and conditional regeneration.

What this study also wants to make clear is that the body and its boundaries are not simply ‘managed’; in significant ways the shifting notions of bodily inviolability are also an active, inventive and influential force. The transplanted body signals new understandings of death, life, immortality, and resurrection. It initiates new conversations about hope and faith, vocation and duty, miracle and morality. It engenders new relations, genealogies, and groups and unfamiliar yet intimate bonds between them. It sparks new rites and new employments of ritual language, gesture and space. It inspires new paths of growth, transformation and knowledge. In short, the transplanted body generates a religion of organs that affords many insights into the nature of religion in modernity.

Methodology

My dissertation is an ethnographic study of religion as conceived and experienced by organ transplant participants. It is also a cultural study of North America’s collective expressions of transplant as found in Christian journals, popular media, advocacy literature and public policy statements. Central to this study are a series of 40 interviews conducted primarily with transplant recipients, but also with potential recipients, recipient family members, living related donors, transplant professionals and advocacy personnel. The absence of donor kin from this list is a serious omission. Early on it became clear that the paired events of donating or receiving an organ involved such different narrative trajectories, such dissimilar experiences of family and body, such contrasted meanings of
life and death that one small research study designed to elicit a limited number of 
intimate consultations could not do justice to both ends of the transplant exchange. The 
focus of this study is on narratives of illness, the death of organs, and the experience of 
transplant.

It has this focus for a number of reasons. One is the illness narratives of my own 
family. My father, my husband and my uncle have all dealt with end-stage renal failure 
and they all have transplant stories – although not the robust transplant stories that are 
generally favoured both by popular media and by transplant advocates. My father was 
ineligible for transplant due to other complications, my uncle died waiting for the 
arangements for a live donor to be finalized, and my husband who was always 
ambivalent about transplant, who turned down an offer of a live donation and reluctantly 
proceeded with a cadaveric transplant after waiting 7 years, rejected the organ after 11 
months.

My familiarity with renal disease and organ transplant has made it relatively easy 
to gain access to organ recipients. But it does not alleviate the difficult task of being both 
a part of this collection of transplant stories and a scholar apart from it. Many of the 
recipients I have listened to are ardent activists for organ donation awareness, and many 
of the scholars I have listened to are passionately concerned about the excesses of 
donation campaigns and strategies. I have struggled to find my place in the politics of 
organ transplant. Privileged with the stories of organ transplant recipients, I don’t want 
to fall into a ready made critique that adds more pain to what are already tremendously 
painful stories. But neither do I wish my sympathy for these stories to blind me to the 
negative realities and potentialities of the technology that scholars have pointed to. The
narratives my own situation predisposes me to hear, and the narratives that my voice lends itself to shaping, have been narratives of organ failure – the death of the native organ that is so rarely talked about in transplant discourse. I hope that my attention to these narratives of organ death questions both positions: the too easy assumption that transplant ‘fixes’ things, and the too easy assumption that one should not attempt to fix things.

Interviews with transplant participants were complemented by field research undertaken at transplant athletic contests, organ donation awareness events, donor memorials, camps created for organ recipients, dialysis wards and transplant support group meetings. Much of this field research was conducted in southern Ontario, largely in Toronto but also in smaller centres such as Hamilton, Kitchener and London. I made several trips to Camp Dorset in the Muskoka region of northern Ontario. Camp Dorset is a vacation retreat for patients with renal failure, for persons who have had a kidney transplant, and for their families. The advantage of interviewing persons here was two-fold. I was able to interview potential and realized transplant recipients from regions and hospitals across Ontario. This diversity produced highly contrasted urban and rural narratives. I was also able to witness the interactions and the ritualizing of this ‘kidney community’. Many of my respondents attested to the existence of a transplant community, but in this locale I was able to engage with it.

I also experienced the transplant community firsthand as I paddled with “Team Transplant”, a group of organ recipients that compete in Dragonboat tournaments under the auspices of the Canadian Transplant Association. Considerably further than the 500m we travelled across various stretches of Lake Ontario (but far less demanding!) were my
excursions to Sherbrooke, Quebec where I witnessed the first annual Canadian Transplant Games and North America’s largest organ donor recognition event, a memorial service hosted by an organ donation advocacy group.

The collective expressions of organ transplant were tracked through select popular artefacts (public policy statements, promotional materials, samples from popular media and articles in Christian journals) that demonstrate core cultural narratives concerning organ transplant. Comprehensive coverage of the multiple entries on organ transplant was not possible. I concentrated on providing a representative sample from both visual and textual media. I analysed examples from entertainment, advertising and news, examples demonstrating both high and low aspects of North American culture. In some instances my study was quite systematic, deliberate and thorough – as in my examination of organ transplant in popular Christian journals, my coverage of Canadian advertising campaigns to promote organ donation, or my review of popular movies with transplant themes. At other times – such as my exploration of transplant publicity and transplant on TV -- my media study was ad hoc and localized, guided by happenstance and the media encounters of my study’s participants.

In my interviews with transplant recipients the subject of religion was expressly pursued and in my evaluation of both individual narratives and collective expressions of transplant the lens of religion is consciously employed. In significant ways my study cannot be considered representative. The recruitment process for this project was not designed to ensure a random sample of transplant recipients. Potential participants were told that the study was interested in questions of religion and several participants came forward precisely because they wished to talk about the religious dimensions they
perceived in their experience. Further, almost all of the recipients I spoke with were of Christian heritage and/or affiliation and very active producers, as well as consumers, of transplant advocacy.

**Organization**

This study is organized into five chapters. The first chapter reviews mainstream Christian literature to complicate the assumption of Christian assent to organ transplant. Scholars of religion have begun to bridle at the consistently supportive position attributed to faith traditions. Mongoven (2003) has remarked: “One can only wonder what psychology allows public officials brazenly to repeat what appears a bald lie” (101). The literature shows a complex history of extremely enthusiastic lay and ecclesiastical support consistently met by Christian voices of concern, caution and dissent. Whether positive or negative, Christian renderings of transplant are especially important because they have dramatically influenced the public perception, language and vision of organ transplant. However, the incongruity of North American ethnic and religious diversity and the predominantly Western and Christian assumptions that underlie much transplant policy and most donation appeals has just begun to surface. My first chapter locates the roots of the Christian embrace of transplant, and the Christian misgivings about that embrace, in a multi-vocal 20th century conversation about the ethics of medicine. While it fails to make other religious traditions fully present, it does ask what their absence from the transplant scene bodes.

Deepening, complicating and expanding the interface of faith traditions with organ transplant is helpful. But it does not begin to discover the lived religiosity of
transplant recipients and donors, nor does it engage and evaluate the implicit or civil
religion of organs that surfaces in the collective North American narratives and rituals of
transplant. In the second chapter I examine the spiritual dimensions of recipients’
encounter with death in a particular early 21st century terrain shaped by the practices and
discourses of biopower. I discuss the “somatic ethic” as it transpired in organ recipients’
determination to live ‘fully’, yet responsibly, in the awareness of death and in
communion with others so afflicted. Attending to spiritual communities and connections,
eschatological visions and rituals of remembrance can illuminate the dichotomous
categories of gift and commodity that have largely organized evaluations of organ
transplant. It also calls attention to the need to conceptualize religion as a part of
contemporary bio-societies and a factor in the circuits of biotechnology and biovalue.

The confrontation with death and the inklings of immortality were central to, but
not exhaustive of, participants’ religion or spirituality. The third chapter explores the
‘wondrous’ in the accounts of these organ transplant recipients -- visions, presences,
unusual emotional states, dramatic conversions, prayers answered with prescient timing
or astonishing results. I explore the role of the religious encounter in the affirmation of
participants’ moral character. Chronic illness and organ transplant create tears in both the
bodies and lives of recipients, tears that are mended, in part, by the cultivation of new
virtues: perseverance, discipline and courage. Attending to the wondrous (both the
strange and the awesome) in the accounts of organ recipients illuminates the dominance
of health in our common cultural assessments of morality and suggests that assertions of
religious experience and inculcations of spirituality may encode alternate moral visions
and a distinct moral community.
The fourth chapter considers the ritual body [some] transplant recipients acquire and its correlate – the collection of ritualized agents that define the transplant community. The rituals of transplant are both a private and a public phenomenon, for they blend, in complex and diverse ways, private lives and public spheres. I explore the individual cultivation of transplant rituals (“ritualizing”), transplant’s established rites of decorum, and transplant’s formal ceremonies. Each offers determined, yet distinct, redress to the significant breach posed by organ failure and a treatment modality that engenders still other social, spiritual and physiological ruptures. And each performs the intimate and private in public spaces and in conjunction with very public discourses: about morality, about transplant, about healthcare and about the nation.

The ritual rhythms of the transplant body are one way a ‘religion of organs’ is made manifest in the contemporary public sphere. Another is the prevalence of religious language, spiritual motifs and moral discourses in the media portrayals of organ transplant. The final chapter tracks the sacralized discourse of transplant advocacy (advertising, publicity and media-tized rituals) and the echoes and rebuttals of this discourse in movies and television shows about organ transplant. Sanctified transplant advocacy builds on a number of identifiable religious currents – Christian notions of agape, the resurrection and healing miracles of Jesus Christ, intimations of angels, immortal souls and divine intervention, and the miraculous impulse of love expounded in the New Age doctrine of A Course in Miracles -- but is simultaneously the product of sophisticated social marketing that relies on a moral logic of sin and salvation to sell organs as public goods. This mixed pedigree meant that while recipients did construct bona fide individual belief systems and moral identities from the media’s repertoire of
sacred transplant symbols, they were also interpellated, or hailed, by media identities that are ‘ready-made’, sponsored by social elites, and given moral authority by the religious vestments they sport. The media’s ‘religion of organs’ proffers a complicated solace to recipients whose bodies and identities have been disrupted by transplant technology and whose moral character has been questioned by the ambiguities inherent in both chronic illness and foreign body parts.

Organ transplant does not just reconfigure bodies; it leaves its mark on the religious landscape of contemporary North America, a strange scene of sacred and secular, a landscape rife with religious pluralism, competing cultural narratives, individual syncretism, the prominence of the body, and of healing as salvation. These five chapters -- Christian perspectives on this medical technology, religious understandings evolving from a (post)modern death, the connections between religious experience, illness and moral identity, the ritual rhythms of the transplant body, and the intersection of media and religion – demonstrate the various ways that the resurrected bodies of transplant recipients provide a window on contemporary religious meanings, practices and experiences.

1 Canada has been slower than the United States to accept organ donations from living anonymous donors (live donors emotionally and genetically unrelated to the recipient). However, living anonymous donors are almost certain to become more common in the near future. British Columbia Transplant has conducted a pilot study involving kidney donation from ten living anonymous donors and the Multi-Organ Transplant Centre of the University Health Network in Toronto has likewise recently completed some of their first kidney transplants from a living anonymous donor. Living anonymous donation raises the spectre of payment for organs, currently illegal in North America.

2 Lock’s (2002) is an extensive social scientific treatment of the concept, its medical establishment, legislative history, and cultural reception.
3 Donation after cardiac death (DCD), although controversial, has increasingly been implemented in the United States and in several European countries. Protocols are evolving in Canada. DCD involves the decision of family and medical professionals to withdraw life-sustaining therapy from intensive care patients suffering from what is deemed to be a non-recoverable injury or illness (but who are not brain-dead). Preparatory chemicals are administered to the patient, transplant recipients are readied, and within minutes of life support being removed (and cardiac death transpiring), organ procurement proceeds. “Non-heart beating cadavers” is another term for this type of donor.

4 Some provinces now reimburse living donors for costs associated with the donation of an organ. Some commentators (Sharp, 2008) feel such payments, even if nominal, erode the ethos of voluntary donation, entice us to think of organs as commodities, and move us closer to market solutions for organ shortages.

5 figures are from CORR (Canadian Organ Replacement Registry) 2007 Preliminary Report.

6 It is anthropologist Nancy Scheper-Hughes who asserts that organ transplant has re-conceptualized relations between these three bodies. She argues that these re-conceptualized relations should be central to anthropological investigations of organ transplant (2000, p193).


9 Fiedler (1996) argues that it is precisely the unconscious remnants of religion and culture that provide resistance to organ transplant.


11 See “Pastoral Guide to Organ and Tissue Donation” published by Organ Donation Ontario (1998) which featured a section entitled ‘Reaching your congregation and community’ and offered advice such as speaking out in favor of organ and tissue donation in sermons, scheduling speakers for educational programs, inviting transplant participants to share their experiences, and including donor cards in church newsletters. The Golden State Donor Services, California’s organ procurement agency, produced a luxurious four-colour brochure meant to encourage and guide faith organizations in Donor Sabbath services. The advertising agency that produced ‘Donor Sabbath – Live Begins With A Gift’ received a prestigious national advertising award.

12 I am indebted to Casanova’s (1994) review of secularization literature and in particular his division of this literature into the three broad critiques of religion in modernity that I outline.

Clifford Geertz’ (1965) definition of religion as a cultural system is perhaps the most influential of a series of functional definitions of religion.

See Veatch (2000), O’Connell (2001), the compilation of traditions introduced by Wiest (1991), and the multi-authored surveys of religious faiths found in specific issues of Transplantation Proceedings (1990, 1988) that deal with ethical concerns about transplant. A particular faith tradition’s ‘perspectives’, ‘views’ and ‘conceptions’ of transplant are sometimes found in social scientific reviews of transplant (see Dorff, 1996), but such articles also propagate the notion of religion as official moral proscription. The collection of articles edited by Youngner et al (1996) is devoted to uncovering the “symbolic and anthropomorphic meanings of human organs exchange”, but this endeavor remains on the level of the symbolic and fails to access the lived religiosity of transplant participants.

O’Connell (2001) examines 17 Christian sects, but does not mention Confucianism or Taoism, does not distinguish between Sunni or Shi’ite Muslims, and devotes less than a paragraph to Hinduism. Judaism and Christianity have multiple pages devoted to each religion in the Wiest (1991) compilation whereas Buddhism, Hinduism and Islam receive less than a page each. Veatch (2000) tries to correct some of the imbalances.

The ACDO organ donor memorial service held annually in Sherbrooke, Quebec, designates organ donors as “ambassadors of health” and considers their donation to be a “legacy of health”.

Robert Orsi’s (1996) treatment of the cult of St. Jude is particularly instructive.

Sharp’s later work (2006) offers a ‘generative’ reading, exploring these commemorative events as a form of memory work.

Foucault remarks that these two levels “constituted the two poles around which the organization of power over life was deployed” (1976, 139). The administration of life executed through organ transplant strategies is likewise distributed at both the level of the individual (the explicit disciplining of individuals to sign their donor cards, for example) and the level of population (the calculation of organ donor rates per capita or the elevation of a generic organ donor as social model). When the perspective of ‘population’ is engaged, as it is in “the greening” of organ transplant, Sharp is correct to note the subsuming of the individual donor.

See Foucault (1976) on eugenics as a logical outcome of biopower. See the complication of this position in Rose & Rabinow (2006). See also Dickinson (2004) for an exploration of the benign, even liberal, positions advanced by biopower.
Chapter One: Christianity & Organ Transplant

Organ Transplant

“St. Catherine Exchanging Her Heart with Christ” by Giovanni di Paolo

1. Christ reaches for the sinner’s heart, hands back his: Catherine leans into wings unseen, heart in hand, looks across his shoulder to a place in air – sees just beyond us something we cannot: her heart his, his heart hers.

2. Giovanni di Paolo shows what to do: take charge of our disorder, sever, renew the heart—but who gives up salt, makes every day Friday, who has the heart for this white-gowned protocol when faith and dare seem all the same.

Robert Bense

The contradictory images and conflicting emotions raised in Bense’s “Organ
Transplant” leave one wondering -- what do Christians believe about organ donation and
transplant? This chapter attempts to answer, in a limited fashion, this broad but important
question. There are several inherent difficulties. The designation ‘Christian’
encompasses a wide range of sects and varying degrees of commitment and affiliation. It
can reference institutions or individuals, leaders or lay people in any corner of the globe.
Accessing what this amorphous group ‘believes’ is equally fraught with methodological
quandaries. A definitive answer to such a question is not possible.

That said, this chapter attempts to add to existing understanding of Christian
perspectives on transplant in North America. First, it examines the most prevalent and
public assertions of Christian assent to transplant, those marshalled and presented by
government sponsored organ procurement agencies, and asks how this particular version
of Christianity is constructed and why. Secondly, it attempts to expand both the
repertoire of Christian voices and the intricacies of Christian thought by carefully
tracking the theological discussion on organ transplant as it appears in Christian journals
published in North America from 1980 to 2000.¹ A review of Christian literature
concerning transplant technologies and public policies of organ exchange shows a
complex history of extremely enthusiastic theological, scriptural and ecclesiastical
support consistently met by Christian voices of concern, caution and dissent. What
becomes equally apparent is that Christians are not merely elaborating their acceptance or
rejection of transplant technologies; organ transplant has become a technological
platform and imaginative vista on which Christians articulate conceptions of body,
person, death, community, morality and God.²
The second, and obvious, question is ‘why Christians?’ Why exclude the vast range of religious traditions and their varied stances on the issues of transplant and donation, especially given the pluralistic nature of North American society? The incongruity of North American ethnic and religious diversity and the predominantly Western and Christian assumptions that underlie much transplant policy and most donation appeals has just begun to surface. A recent article cautions that the research on donation in Canada has not been sensitive enough to the role or plurality of religious belief (Bowman, Richard 2004). Bio-ethicist Robert Veatch’s (2000) latest publication on organ transplant is largely drawn from his existing work, but information on non-Western religious traditions was newly written and researched (ix). Slowly, but surely, transplant professionals, procurement agencies and advocacy organizations are beginning to realize the importance of engaging diverse religious viewpoints and populations. In 2000 a group of transplant professionals from a British hospital system organized “the first ever conference looking at organ donation and transplantation from the multi-faith perspective” (Bradford 2000, 4). The federal government of Canada sponsored its own inter-faith forum in March of 2005 (Canadian Council for Donation and Transplantation 2006).

Much of the emergent attention to non-Christian understandings of transplant is directed to discovering (and overcoming in many cases) perceived religious barriers to organ donation. No doubt these exist, as they do even in Christianity, and it is useful to have a fuller appreciation of them. But even if religious barriers could (or should) be removed, donation would not necessarily follow. What has been unique about Christianity’s role in transplant discourse is its ability to encourage donation, to lend
religious voice, vision and evangelism to the transplant endeavour both within and without the bounds of ecclesia. The coupling of Christianity with secular donation appeals and public policies has no doubt won adherents – but does it capture the devout of other religious persuasions?

This is an important question. Despite increasing volume, proliferation and funding of organ donation appeals, organ donation rates have not significantly increased and donation rates amongst Canada’s ethnic populations are persistently low. This has not occasioned a review of existing Christian based appeals and their ability to motivate Canada’s diverse ethnic and religious populations, but a growing frustration with the perceived insufficiency of voluntary donation and increased advocacy for procurement strategies based on ‘presumed consent’ or what has been called by some bio-ethicists “routine salvaging” (Veatch 2000). More common in Europe, this kind of procurement presumes that all persons with an opportunity to donate organs upon death willingly assent to do so – unless they have expressly declared otherwise at some time prior to their death. Presumed consent raises any number of ethical issues, but may be particularly pernicious to the many Canadians whose understanding of organs, death and transplant are shaped by forces other than Christian and western narratives of the body (Bowman, Richard 2004, 275). Accessing, and respecting, varied religious attitudes to organ transplant may be critical both to successful donation appeals and to equitable healthcare policies and protocols.

There can be no doubt that research on the relationship between organ transplant and non-Christian religious traditions is vitally important. At the same time, it is not immediately germane to this project. The central aim of this research is to examine
religious dimensions of the recipient experience, as evidenced in ethnographic research conducted with this particular group of participants. My recipients were almost exclusively of Christian background. Half identified as active participants in Christian congregations (although this did not encapsulate all of their spiritual activities, many of which centred around transplant ritualizing). The other half, with one exception, identified Christianity as the faith of their family or childhood. One person identified as agnostic and considered her upbringing agnostic. A variety of Christian denominations were referenced: Anglican, Catholic, Baptist, United Church, Salvation Army, Orthodox Church and one independent evangelical sect. Only one recipient reported religious influences from a non-Christian tradition, incorporating into his daily life some Tibetan Buddhist rituals absorbed from his girlfriend’s family. One recipient reported the influence of New Age doctrine on her primarily evangelical Christian beliefs.

Christian dominance among the other transplant participants in the project – persons awaiting transplant, persons declining transplant and live donors – was equally pronounced. Of these ten participants nine were of Christian origins (the exception being a Jewish man with an ambivalent relationship to Judaism) presenting a similar variety of sectarian diversity extending to Jehovah Witness and Mennonite affiliations. The sheer dominance of Christian subjects in this study makes an appreciation of non-Christian traditions peripheral while clearly underscoring the need for a nuanced understanding of Christian entanglements with technologies of transplant.

The second aim of this study is to examine the sacralized media discourses that organ transplant engenders. It is my contention that Christianity heavily inflects these discourses. The metaphors and allusions – the gift of life, body as sacrifice, body as
redemption, care for the stranger – used in the public and professional sphere to rationalize transplant and encourage donation have indelible links to Christian scripture and theology (see LaFleur 2002, Hogle 1999, Lock 2002). Christian renderings of transplant are especially important because they have dramatically influenced the public perception, language and vision of organ transplant. While review of these sacralized media discourses is the subject of another chapter, close examination of Christian attitudes to organ transplant is a necessary foundation.

*Christianity and Organ Transplant Advocacy*

I believe we come very close to being ‘Christlike’ on the day we make the decision to sign our organ donor card and give of ourselves. Being an organ donor reconfirms our Christian values.

- liver recipient, Christian

Quote from *Donor Sabbath. Life Begins with a Gift*. Publication of Golden State Donor Services

The sumptuous four-colour booklet *Donor Sabbath -- Life Begins with a Gift* is a reverent fusion of photographic homage to religious practice (a candlelit crucifix, close detail of a Buddhist shrine, an Orthodox priest surrounded by brass candle stands) and textual affirmation of the religious values embedded in the practice of donating organs. “By giving your most sacred gift and becoming a donor, light replaces sorrow, and life for those who wait begins anew”, the pamphlet states. Lanterns, candles and rosy red paper stock reinforce the message that organ donation is indeed a hallowed gift of light, life, compassion and kindness. “Religions worldwide emphasize compassion,” reassures the copy, and if the devout have any uncertainty about their church’s stance on organ donation they need not: “The truth is, all major religions support this act of charity and consider it a beautiful gift”.
Donor Sabbath, Life Begins with a Gift is a publication of California’s organ procurement organization, Golden State Donor Services. It can be seen as one of the most creative entries in the field of organ procurement outreach to religious practitioners and organizations. In both Canada and the United States organ procurement organizations have actively advocated for the endorsement of religious institutions and the allegiance of religious practitioners. They have undertaken attitudinal surveys of religious leaders (Gallagher 1997), extended education and outreach to religious congregations, promoted ‘Donor Sabbaths’ or similar services, and promulgated positive information about religious views of organ transplant.

Procurement agencies are cognizant that religion plays a potentially powerful role in the acceptance of organ transplant and donation. As one review stated, “the level of influence pastoral caregivers have is very significant and should not be overlooked. Clergy represent an enormous group of untapped allies who can assist with the challenging task of helping families discuss donation” (Gallagher 1997, 220). But organ procurement agencies are equally aware that religious unease about transplant and religious injunctions against donation can also play a powerful role in the rejection of transplant technologies. As Gallagher (1997) indicated, brain death in particular is problematic for religious leaders with 25% of clergy responding that they were uncertain about brain death or believed organ donors are not really dead. Religion, for organ procurement agencies, has required a dual approach: they have sought to increase organ donation by harnessing religious motivation while simultaneously working to uncouple religious misgivings from transplant technologies.
The motivational campaign has several facets, each of which seeks to inscribe organ donation and transplant with religious resonance, symbolism and values. Theoretically organ procurement agencies seek religious allegiances across faith traditions, but given North American demographics the majority of their efforts, and their most successful endeavours, solicit Christian sympathies for organ transplant.\(^5\)

Publications like *Donor Sabbath* are elaborate and expensive and not the mainstay for most organ procurement agencies. More common is the reinforcement of affinities between transplant and Christianity through various ceremonies. “Donor Sabbath” services are prevalent in the United States where the federal government has developed resources and networks to promote an annual religious service dedicated to organ donation and transplant on a weekend close to the American Thanksgiving (see http://www.transplantawareness.org/sabbath/contents.html). Organ procurement agencies work at the state and local level to encourage Christian congregations to hold such a service and to take advantage of sample bulletins, prayers, responsive readings, scriptural references and sermons the national body has created for the occasion. In Canada, Donor Sabbaths are more ad hoc and localized. The Kidney Foundation representative mentioned that they encouraged Donor Sabbaths close to the Canadian Thanksgiving or at Organ Donor Awareness Week in the spring. Some procurement organizations provide scriptural references and potential sermon topics (see Organ Donation Ontario 1998) and some Canadian congregations made use of the American resources for a Donor Sabbath service (see www.resurrection.cyberus.ca/organ_donation.html, accessed 07/20/2006).

Organ procurement organizations are more directly responsible for donor memorial services, generally conducted annually, to give homage to donors and
recognize the enormous gift of organ donation. These events are explicitly billed as non-denominational, but in my research in southern Ontario they are invariably held in Christian churches and make use of Christian clergy to conduct rituals of prayer and consecration. The implicit message is that Christianity endorses organ transplant technologies and recognizes Christian values in the act of organ donation. This is not a ‘false’ message – certainly the event could not be held in St. Michaels’ Cathedral, as it has been in Toronto for more than a decade, if the Catholic leadership of that institution did not support organ donation. More pointedly, the locale of this non-denominational service reinforces the broader religious sympathy that organ transplant officials would like to cultivate, namely recognition of organ donation as a modern rite of Christian service.

Faith committees and congregational outreach are another aspect of organizational commitment to harnessing religious motivation for organ donation. Essentially, organ procurement agencies conduct these activities because they are anxious for religious leaders to reflect on the strands of their tradition that would support organ donation, to encourage their constituents to consider organ donation, and to be well versed in both the technology and the theology of organ transplant in order to effectively counsel parishioners faced with death of a loved one and the decision of donation.

The Trillium Gift of Life Network, Ontario’s organ procurement organization, and the Central Ontario Branch of the Kidney Foundation described, during interviews with their representatives, faith outreach initiatives they had or were planning to undertake. The Kidney Foundation sent invitations to leaders from various denominations (again predominantly Christian) and hospital chaplains (seen as influential
figures in the donation decision) to “dialogue” with Kidney Foundation personnel and with organ donor kin and transplant recipients culled from the Foundation’s “speaker” lists. Donor kin and transplant recipients with strong faith allegiances were seen as particularly helpful speakers. The intention was to educate religious personnel on both the technological aspects of donation and transplant – what constitutes brain death, what organs can be transplanted, etc. – and the theological impact of donation and transplant in the lives of ordinary individuals.

However, the planned sessions did not transpire. The Kidney Foundation representative quoted scheduling problems, but also noted that religious leaders resisted participating. And hospital chaplains were convinced they were not in need of such ‘dialogue’. Likewise, although the TGLN had been in operation for more than two years at the time of the interview, outreach to faith organizations was still in the planning stages. Although organ procurement agencies and other transplant advocacy groups clearly see the relevance of religion to organ donation, learning to transpose their concerns for increased donation into a register of religious values and theological debates is not always a straightforward matter.

I interviewed a representative of the Kidney Foundation, a management figure at the Central Ontario Branch, who felt a radio talk show host she encountered summed up the difficulty of religious resistance to organ donation.

So we were talking about it and the host said a really interesting thing to me. He said, ‘You know, I have my own religion, but what I don’t understand is how people use religion like a Chinese menu. And they pick and choose all of the things that they think they should follow--

Macdonald: #13, #47, but not # 6

That’s exactly how he put it! And I thought, you know what, that’s so true. Because his point was if you’re whatever religion, for you to honestly say ‘I’m Anglican’, ‘I’m a Catholic’, ‘I’m Jewish’, whatever, you should be following all
the tenets of that religion. But people don’t. They follow the ones that suit their lives…

And, it echoes in my head sometimes when I hear people talking about religion.

Macdonald: selecting of this one [aspect] and weeding out that one

Exactly. But I think people do that with organ donation. If they make the assumption that my faith won’t fit -- if they’ve sort of made up their own minds on what they think about organ donation -- they won’t investigate it further to see if that’s really the way their religion as a whole supports it. They’ve made their decision and they will use that one [aspect of religion] to back up whatever argument they want to make.

So, yeah, it’s quite fascinating to me how people use their religion with organ donation.

I do not know if would-be donors scan their religious traditions like a Chinese menu when considering organ donation; this study doesn’t pretend to look at that decision making process. But there is a distinct irony in the charge of this transplant advocate: if anybody uses religion like a Chinese menu in the debate over organs it is precisely the organ procurement agencies.

Rather than wade into the messy theological tangles that organ transplant generates, the strategy of organ procurement organizations has been to sort religious prescriptions into a list. Those sentiments that mobilize support for organ donation are labelled “Christian” (or Buddhist, Hindu, Jewish or Muslim) while those that impede donation earn the accolade of “myth”, “folk belief”, “superstition” or “mistake”. Organ Donation Ontario (Ontario’s predecessor to TGLN) produced a survey of faith traditions and organ transplant to correct “the mistaken belief” that there are religious constraints to organ and tissue donation (Organ Donation Ontario 1998). Transweb, a non-profit educational website, offers a list of religious faith traditions almost all of which they conclude either support or permit organ donation and transplant. It is acknowledged that
Shinto neither permits nor supports transplant, here “folk beliefs” are said to predispose adherents to view organ donation as injurious to the dead body. The religious information from Transweb is posted verbatim on Health Canada’s official transplant website, however, no entry on Shinto appears. Shinto would seem to be an unpopular menu item.

On the very last page of Donor Sabbath, Life Begins with a Gift there is a stout little statue, a semi-human shape squatting on its haunches, encased in a scaly covering, its facial features recognizably human but heavy and distorted. In front of the creature three small candles are lit, but the picture is cropped very closely, there are no other referents that would allow the idol to be placed in the context of a religious tradition. The page is entitled “Myths” and the title is positioned squarely on the forehead of the strange figure. The copy references the “misconceptions” that surround organ donation. The hope is expressed that “by shining light on the reality of organ donation” (the reality of religious assent to donation) this publication will free potential donors “to follow through with their wishes”. No particular religious belief, practice, sect or tradition is claimed to be a myth, but clearly by implication any that resist organ donation are.
The Chinese menu approach to religion taken by transplant advocacy groups – the selection of choice entries that can be read as complementing organ donation and the skimming over or denigration of unpalatable items – can impede faith outreach endeavours. The Central Ontario Branch of the Kidney Foundation, alarmed at the low donation rates reported for ethnic communities, is currently targeting South Asian, African-Caribbean and Aboriginal communities in the Greater Toronto Area for outreach and educational campaigns. I interviewed the young woman who had been contracted to conduct the initial forays. We spoke about her understanding of religion and how that factored into her outreach efforts. She explained that while organ transplant is not “against” any religion there are all kinds of “superstitions” that prevent people from feeling free to donate. But”, she related to me, “it isn’t always easy to get that across”. At a talk she was giving on a First Nations reserve her distinction between religious
assent to transplant and superstitions that prevent donation generated considerable
hostility. The audience was noticeably discomforted. Finally one man stood up and shot
back at her, “our beliefs have always been branded ‘superstitions’”.

Scholars of religion have also begun to bridle at the consistently supportive
position attributed to faith traditions by transplant advocates. Mongoven (2003) remarks,
“One can only wonder what psychology allows public officials brazenly to repeat what
appears a bald lie” (101). She goes on to critique their use of the term “major” faith
tradition, their refusal to acknowledge traditions suspicious of organ donation, their
assumption that Christians who resist donation because of their belief in a bodily
resurrection are religiously ‘mistaken’, and their equation of religion with belief –
ignoring the traditional death rites that can impede donation even in traditions not
theoretically opposed to donation. Mongoven (2003) notes Christian Science is not
enthusiastic about transplant and Jehovah Witness does not encourage organ donation
and instructs adherents that they may receive an organ only if the transplanted organs and
tissues are completely drained of blood. Allen Verhey (2000) comments on Mormon
concerns about literal resurrection and the lack of official Mormon policy on transplant.
Resistance to donation among African Americans is sympathetically explored by Cheryl
Sanders (1995) who refuses to construe black Christian concerns for bodily resurrection
as “religious myths and misperceptions” as others have, notably Clive Callender, director
of the Transplant Center at Howard University (see Veatch 2000, 8).

These scholars are correct to complicate the picture of Christian assent to organ
transplant. To be sure, there is a wide swath of Christian literature and a plethora of
Christian leaders that speak evocatively of the Christian truths, lessons and practices
contained in the transplantation of organs. But even the most unequivocal Christian supporter of transplant has caveats about organ exchange. Further, a considerable amount of the Christian discussion is decidedly ambivalent about organ transplant, and a smaller contingent decidedly alarmed about transplant potentialities. There are widely held Christian tenets, including but not limited to the bodily resurrection, that are challenged by technologies of organ transplant. And it should be underscored that the voices of caution and concern do not solely, or even predominantly, belong to Christian traditions or ethnicities that have been marginalized; they speak from the very centre of white, mainstream Christianity, from both left and right-leaning persuasions.

A review of Christian journals from the period 1980 – 2000 reveals certain components of scripture and theology that are central to the discussion of organ transplant: the Christian view of death, Christian responsibility to God’s creation and to his creatures, the meaning of Christian community, and the shape, role and life of the Christian body. Long centuries of Christian thought inform these questions, but so too do 20th century advances in biomedicine and bioethics. The balance of this chapter explores the multivalent ways that transplant has shaped Christian understandings and the post-modern context in which Christians pose these questions. What becomes apparent is both the impossibility of a uniform Christian response to organ transplant technologies and the importance of organ transplant to 20th (and 21st) century conversations about the meaning of Christianity.
Christianity, biomedicine and bioethics in the 20th century

Prior to the early 1980s when the development of the anti-rejection medication Cyclosporine made organ transplant a truly viable and increasingly practiced modality of treatment, public, bioethical and religious debate centred on other medical and bodily dilemmas than the saving of lives through the transplantation of solid human organs. Long-standing arguments about the public and collective responsibility for health care build through the 1950s and culminate in the 1960s in U.S. programs like Medicaid and policies like Canada’s 1966 National Medical Care Act. Long before debates about the propriety of sharing organs, a successful argument was mounted in religious and secular circles that society does owe care to the sick and suffering; indeed, we are our brother’s keeper.

But with this resolution on universal healthcare comes a growing recognition that the resources to keep one’s brother are unavoidably limited and the choices about those resources, given our collective responsibilities, fraught with difficulty. The technology for hemodialysis was invented in 1961 and Life published a widely read article in 1962 entitled “They Decide Who Lives, Who Dies” regarding the limited spaces for renal dialysis in Seattle. 1969 saw a spate of important publications on the allocation of heroic medicine, including Nicholas Rescher’s “The Allocation of Exotic Medical Life-Saving Therapy”. In 1970 Kenneth Vaux edited a collection of articles entitled Who Shall Live? Medicine, Technology, Ethics, and Christian ethicist James Childress published “Who Shall Live When Not All Can Live?” A widely distributed film of the same year, “Who Should Survive?”, charted the short life story of a newborn with Down’s syndrome who is allowed to die.
To have the technology and the responsibility to provide care, yet insufficient resources to care for all, is an ethical dilemma several decades old and still central to today’s heated discussions of healthcare funding and reform. So while Nancy Scheper-Hughes (2000) rightly admonishes that we must examine more closely the rhetoric of “scarcity” that pervades transplant discourse, it is nevertheless helpful to note that alarm about shortages entered bioethical and religious reflections long before organ waiting lists and is inextricably tied to our acceptance of the mandate for public healthcare.

In the same decades another pervasive concern occupied ethicists, both religious and those from the swiftly forming discipline of bioethics. In the aftermath of World War II outrage at Nazi medical experimentation was added to the newly emerging postulations of human rights and the two foci result in intense scrutiny of medical research and a growing literature defending the rights of patients. Codes of medical ethics proliferated. The World Medical Association, The American Medical Association, the Catholic Hospital Association, the American Nurses Association, the British Medical Research Council, the National Institutes of Health, and the American Psychological Association produced codes or memorandum on medical ethics, health research, and clinical investigations in the years between 1949 and 1953. Pope Pius XII issued the Moral Limits of Medical Research and Treatment in 1952. In 1956 a California malpractice case was the first to employ the phrase “informed consent”. The imbalance of power between the bodies of the weak, the ill and the dying and the very structures of medicine is the central concern of such codes. The codes both guard against the inequities of power in the care of the sick and draw attention to them; certainly they
cannot reverse such imbalances, and fears about the autonomy and rights of the patient continue to surface.\textsuperscript{8}

In transplant discourse the brain-dead organ donor is the most visible victim of biomedical ascendancy and arrogance (see for example Schepers-Hughes 2000). Concern for the full and informed consent of living donors is also prevalent, however, the vulnerable position of the recipient vis a vis the medical establishment is rarely commented on. Linda Hogle (1999) writes persuasively about the lingering effects of Nazi medical experimentation on transplant misgivings in contemporary Germany. While transplant misgivings in North America do not specifically cite Nazi war crimes, they are informed by the ethical convictions those crimes inspired on this continent. These predominant strands of mid-20\textsuperscript{th} century Christian ethical and theological discussion -- a commitment to caring for society’s sick, an alarm for the sick that cannot be saved, and a fear for the sick and the dying exposed to the unbridled passions of modern medicine – remain very influential in the theology of transplant.

\textit{Christian Theology and Organ Transplant}

\textit{Life and Death}

When he had said this, he cried with a loud voice, ‘Lazarus, come out’. The dead man came out, his hands and feet bound with bandages, and his face wrapped with a cloth. \textit{John 11: 43-44.}

Death is the pre-eminent backdrop for the transplantation of organs. There is the averted death of many organ recipients. There is the tallied deaths of those transplant did not reach and those transplant did not save. There is the fear of death that accompanies the recipient and their live donor alike to the operating room. And there is the unexpected and uneasy death of the brain-dead donor. Margaret Lock (2002) has
examined the rather nonchalant North American accommodation to this revised definition of death, and this indifference pervades even Christian commentary.

It is indicative of the wide spread acceptance of brain-death that what later commentators worry about are perversions of the criteria of ‘whole’ brain death. Irreversible and complete cessation of all brain activity, the brain-death definition, is the current standard for brain-damaged persons to be considered potential organ donors. But there are voices in transplant debates that call for an extension of the donor pool beyond the stringent demands of brain death to those persons with complete cessation of ‘higher’ brain functions (although they retain basic brain-regulated activities such as breathing) or to those persons with severe brain dysfunction facing imminent death such as anencephalic infants.

Christian commentators concur with medical and legal understandings of death as the cessation of the ‘whole’ brain (see for example Ebersole 1988, Ramsey 1970). But they are quite sharply opposed to any extension of organ donation to the “almost dead”. Pope John Paul II (2000) made it clear that Christian respect for life extends to all those defined as living and the hopes for greater longevity for some does not outweigh this basic prescription (see also Meilaender 1996). “The complete and irreversible cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology”, the Pope stated. Health-workers may ascertain death by these criteria with “moral certainty”. However, the Pope continued, “Only where such [moral] certainty exists…is it morally right to initiate the technical procedures required for the removal of organs” (2000, italics in original). The acceptance of brain-death and the resistance to expanding the current definition of death was uniform across the
spectrum of Christianity, however, evangelical Christians also spoke specifically to the question of anencephalic organ donors. They generally resisted the temptation to extend organ donation to this vulnerable population, again referencing the centrality of Christian commitment to life in all its stages and forms (see Lawton 1992, Clouse 1988, Clapp 1988).

But while Christian commentators are satisfied with the medical definition of brain-death (instigated in large part by the technologies of organ transplant) and clear that transplant desires should not exceed this definition, confusion and dissension about the theological meaning of death is compounded by those same technologies. Some evangelical Christians are quite clear that life is God’s most precious gift, death an enemy to be defeated and organ transplant “a little victory” in the battle (Clouse 1988, 17). In the Catholic tradition human life is the precious gift of God, Teo (1992) notes in support of transplant. Many of his liberal Protestant counterparts concur: “Life, creation, is the original gift of God to his creatures,” writes Davison (1987) in his appeal for Christians to commit to organ donation. Organ donation affords an opportunity to come to a fuller understanding of this theological reality; “reflection on organ donation may remind us how precious this gift of life really is” (1146). “The biblical bias is emphatically on the side of life,” agrees Clouse (1988), and Christians do and should “regard death as the enemy” (20). That enemy is only finally and conclusively defeated, Clause does not fail to note, by Jesus. “But our little victories imitate his great victory in a significant provisional sense”, he adds (20). Transplant, then, in these Christian eyes, is not only life-giving, not only a moral triumph over a mortal enemy, but opens Christian eyes to these realities and affords Christians an opportunity to imitate the life of Christ.
Other Christian commentators on transplant are not so sure that death should be configured as the enemy. Protestant liberals more consistently pointed out that death in the Christian tradition represents finitude and mystery; death calls us to God (Vaux 1984). It is Christian, Girod (2002) insists, to consider the meaning of mortality, to want to reflect on something beyond the continuation of physical life and to hope beyond earthly existence. Such commentators fear that organ transplant might disallow these Christian insights about life beyond death and disregard the inevitability of death. “After all,” Girod (2002) adds, with reference to Jesus’ famous resurrection of Lazarus, “everyone brought back from ‘death,’ whether by Jesus or by modern medicine, will eventually die again” (33). For some Christians, organ transplant defies the Christian meaning of death. “One acquaintance told me,” relates heart recipient Clouse (1988), “he could not believe that I, a devout Christian, did not choose simply to die” (19).

Many Christians are well aware of the double meanings of death – both enemy and sacrament -- encoded in Christian scripture and doctrine. Refined theological treatments attempt to hold the alternate meanings together (see Meilaender 2000 for a helpful review). But even when Christian commentators are scholarly or sophisticated enough to recognize the theological continuum, “balance” means different things to different observers. Meilaender (1996) suggests that organ transplant deserves critical Christian scrutiny and should, in many instances, be declined. “Christians know death as an evil and the last enemy, hence temptation to do whatever could be done is understandable,” Meilleander writes, “but should be balanced by trust and courage that will enable us sometimes to decline to do what medical technology makes possible” (1996, 37). Davison (1987) likewise acknowledges that no temporal or atemporal means
could or should prevent God’s intended end for humans, but argues temporary extension of life, such as that gained by organ transplant, is in keeping with Christian vision.

“Although Jesus raised Lazarus, Lazarus will die again”, he writes, “but in the meantime Jesus has extended his life, offering new opportunities for Lazarus and his family” (1147).

While organ transplant has occasioned new Christian debates about the meaning of death and the advisability of combating it with biomedical means, transplant is also embroiled in the long-standing Christian wrangling about the beginning of life. Transplantation of fetal tissue and stem cells (which are derived from embryos and fetal tissue) is a relatively new application of transplant that holds tremendous potential for the treatment of Parkinson’s, Alzheimer’s, diabetes and other diseases and injuries. Fetal tissue and stem cells have less potential for rejection than adult tissue and are able to develop into requisite kinds of cells absent or diseased in the recipient. For instance, the transplant of fetal brain cells implanted into the brains of Parkinson’s patients occasions the regeneration of dopamine in the brains of these patients, alleviating the symptoms of the disease far more effectively than existing drug treatments.

What agonizes Christians (predominantly evangelicals) about this modality of transplant is the source of most of the cells used in research and treatment: aborted foetuses. The transplant of tissues from unborn babies places transplant squarely in the centre of Christian concerns about abortion. Those concerns are well noted, but fetal tissue transplant adds new fuel to the fears of Christian pro-life proponents, fears abundantly reported in the evangelical Christian commentary on transplant. If the aborting of the fetus is unjust, how much more unjust is it to subsequently invade the
unconsenting bodies of these babies? Will trauma be inflicted on bodies not yet dead? Will women be manipulated into abortions or encouraged to have later abortions for the sake of appropriating fetal tissue? Will commercial exploitation insinuate itself? Will fetal tissue transplant erode the emotional stigma of abortion by giving the mothers the salutary title of ‘donors’ and fetal tissue the connotation ‘gift’? Will ultimately more babies be aborted? (See Anonymous, Christianity Today 1988; Post 1988; Lawton 1988, 1992; Simons 1990; Fish 1990; Arant 1990.)

These fears are persuasive and evangelical Christians have been intimately involved in the U.S. legislative process that, until very recently, had frozen research on fetal tissues obtained from induced abortions out of public funding. However, there is not unanimity in the Christian community on the ethics of this medical issue, despite its close ties to abortion. Lawton (1992) reports division on fetal tissue transplant -- the benefits of cure that this new transplant technology proffers are sufficiently connected to Christian commitment to saving lives as to produce fault lines in the evangelical community. Lawton (1992) documents a southern U.S. Baptist minister in congressional testimony on the subject who points to Adam and Eve as ‘transplant buddies’: “not only does God approve of tissue transplant, but he himself performed the first one. As long as abortion is legal using the tissue is a pro-life initiative” (41).

In some ways, fetal tissue transplant is outside the purview of transplanting solid human organs. However, Christian concern for the life of the unborn also pervades stem cell research, which is more directly tied to organ transplant. Embryonic stem cell lines are developed from eggs fertilized in in-vitro fertilization clinics but never implanted in a woman’s uterus. The resulting embryos are frozen and later donated for research
purposes with the informed consent of the donors. What disturbs some Christians is that the procurement of stem cells destroys the embryo and the human life it contains. What excites medical researchers is the potential for stem cell research to lend itself to growing organs for transplant through technologies of cloning. (This modality is referred to as therapeutic cloning to distinguish it from attempts to clone a human being.) Therapeutic cloning sees the patient’s own cellular material inserted into a female ovum from which the nucleus has been removed. From the resultant embryo a stem cell line is developed that might one day be cultivated into an organ that could replace failed or damaged organs in the patient. Containing the patient’s own genetic material the transplanted embryonic stem cells would not likely be rejected. Currently, immunosuppressant medications (with numerous serious side effects) are prescribed to all recipients in order to combat the almost certain rejection response.

The concern with therapeutic cloning, state several Christians and ethicists in unison, is that research involving cloning techniques may very well further aspirations and means to the cloning of human beings. Christian aversion to use of embryonic materials combined with Christian concerns about the uniqueness and dignity of human persons make this avenue of stem cell research even more troubling than fetal tissue transplant and equally of import to liberals, conservatives and evangelicals. Pope John Paul II (2000), while endorsing brain death and the transplant of organs freely given, speaks out strongly against experimentation with new therapies “that fail to respect the dignity and value of the person” and in particular denounces “attempts at human cloning with a view to obtaining organs for transplant”. (See also Nazir-Ali 2000, Meilaender
The irony of Christian resistance to transplant technologies that would interfere with traditional Christian morality at the beginning of life is that it places even more emphasis on reconfiguring traditional morality at the end of life if Christians are to keep pace with the sick and dying waiting for transplants. Christians will need to engage the myriad technological and legislative innovations aimed at increasing the supply of organs. Some of these, such as the procurement of organs after cardio-circulatory death and the extension of live donation to anonymous donors are too new to have well developed Christian discussions, but there is no doubt that transplant will remain a technology of theological and ethical import.

**Christian responsibility to God’s creation and his creatures**

The Lord God took the man and put him in the garden of Eden to till it and keep it.

*Genesis 2:15*

In his influential book, *The Patient as Person*, Christian ethicist Paul Ramsey (1970) made organ transplant a central component of his review of medicine, patients and Christian ethics. Ramsey enjoined medical practitioners, patients, potential organ donors and Christians to remain ever vigilant against the erosion of a “fleshy” understanding of human persons. He deployed the Catholic rubric of “bodily integrity” to highlight the wholeness of the person, properly understood as both body and soul.

Ramsey’s intent was not to deny the transfer of organs from the willing dead or living donor. The Catholic notion of totality surely considered the part subsumable to the whole, Ramsey stressed. His concern was to establish the ethical grounds on which
invasion of a person’s bodily integrity was merited. Not all transplant opportunities were morally sound, Ramsey argued; issues of full and informed consent, expectations of successful transplant outcome and costs to the donor all bear on the question of bodily integrity and its justified disruption. “Man has the power but he does not have the right to do anything he wants to his own body. His right is that of a steward or administrator of his bodily life” (Ramsey 1970, 166).

In the exchange of organs Christians of varying denominational affiliation have found rich possibilities for the articulation of 20th century Christian stewardship. In addition to Ramsey’s use of the term “steward” to speak about the correct relationship to our bodies, Christian voices have harmonized transplant and stewardship to talk about our relationship to the sick and dying, to our world, and to God.

Caring for the sick is symbiotic with caring for Christ, considers Catholic theologian Bernard Teo (1992). In Teo’s eyes those who donate organs to the weak and dying are both ministering to Christ and continuing his ministry. They are stewards of his flocks. Similarly, Myron Ebersole (1988) believes “organ donation can be a significant way of continuing in partnership with our Creator in the life process” (111). It is a partnership that entails both rights and responsibilities. The rights reference human dominion over the animals and the earth as told in Genesis, his right to shape the world and himself in pursuit of God’s kingdom. “Man is called by God to develop all the potentialities found in nature…organ transplantation is a legitimate extension of humanity’s mandate, the exercise of God-given creativity in the cultivation of natural potentials” (Clouse 1988, 20). The responsibilities extend to the weak, the poor and the sick amongst God’s creatures including, many Christians claim, those afflicted with

The Church has a significant role to play in the encouragement of organ donation, some Christians argue (see Moran 1986, Ebersole 1988). Donor rates, Ebersole (1988) feels, could and should be improved through a church led education strategy that seeks not simply to “inform” but to “transform” people’s attitudes, feelings and motivations. Key to any such transformation, he believes, is cultivating support for viewing organ donation as an act of Christian “stewardship” (109, 112). (For a similar argument that uses stewardship to support stem cell research, see Anonymous 2002).

But if we are partners with the Creator in the life process it is imperative, claim other Christian voices, particularly those of the ethicists, that we establish the terms of that partnership as something other than equal. According to Meilaender (1996) “Not every gift can properly be given by those who know themselves to be creatures rather than Creator” (35). Meilaender (1996) leans on Ramsey’s assertion that we are stewards of our bodies, not owners. As stewards of our bodies, but also as stewards of the world, Meiliendar extols caution. It is a slippery slope we stand on, he warns, “if we permit ourselves to believe that ours is the godlike responsibility of bringing good out of every human tragedy” (35).

And if it is properly Christian to assume the mantle of stewardship in our response to the world, Mongoven (2003) observes, it is surely to all of creation, and not merely to those afflicted with organ failure, that we owe our care. Under this broader conception of stewardship, Mongoven encourages Christians to expand their consideration of equity and justice in the allocation of health care resources. Too often, she claims, transplant
enthusiasts limit themselves to questions of the equitable distribution of organs, rather than properly evaluating the place of organ transplant in a U.S. health system straining to provide even basic care to a large number of its citizens. A thoughtful understanding of Christianity’s true mandate “directs consideration not only to what good the donated organ can do, but also what can be done to preserve health more generally and proactively, and how organ donation fits within a wider web of duties of stewardship” (Mongoven 2003, 110). Indeed, Mongoven’s call for Christians to steward all of creation is echoed in Meilaender’s (1996) concern that our rush to do all of what medical technology makes possible may mean circumstances “where we can save our life or a loved one’s only by destroying the kind of world in which we should all want to live” (37).

**Agape and the useful Christian body**

But a Samaritan, as he journeyed, came where he was; and when he saw him, he had compassion, and went to him and bound up his wounds, pouring on oil and wine; then he set him on his own beast and brought him to an inn, and took care of him.

Which of these three, do you think, proved neighbour to the man who fell among the robbers? *Luke 10: 33-34, 36*

Related, but not identical, to the concept of stewardship is the Christian notion of agape. Agape is the term for Christian love that encompasses the stranger, as in the parable of the Good Samaritan. It is love based on the compassionate recognition of human suffering rather than bonds of affinity, affection or reciprocity. It is, without doubt, the most celebrated Christian rationale for organ donation and transplant, infusing countless media stories of organ donors and recipients and under-girding
much of the advocacy literature, including the pre-eminent invocation of donation of organs as ‘the ultimate gift’. “When scratched even only lightly,” religious scholar William Lafleur (2002) argues, “such a phrase, even when it is passed off as secular, reveals close to its surface the notion of agape” (640).

Agape also features prominently in Christian evaluations of organ transplant. “Alleviating suffering while serving others – both in life and death – is an expression of Christlike loving”, claims Ebersole (1988, 111). Christians are as ambivalent as any group, religious or otherwise, about bodily partition (see Walker Bynum 1991), but, explains theologian Teo (1992), organ transplant reaches into the very heart of Christianity, into the notion of agape, giving Christians a vision of humanity powerful enough to rise above such ambivalence:

Why people care so much for others that they are willing to give the gift of themselves is a deep mystery of human love… For the Christian, such love is a positive response to God’s invitation to every person to love and to human communion. It is to be fully human. (2114)

Christ’s willing surrender of his life, given in compassion for the redemption of humankind, signified by the bloodied and battered body of his crucifixion, is the touchstone of the Christian tradition and the encapsulation of agape. Frequently it is Christ’s sacrifice that commentators refer to when they seek to articulate the twentieth-century version of agape found in the donation of organs. The comparison is evident in the Donor Sabbath quote from the Christian liver recipient, “we come very close to being ‘Christlike’ on the day we make the decision to sign our organ donor card and give of ourselves” and in Ebersole’s (1988) equation of organ donation and Christlike loving. And Clouse’s (1988) declaration – “There are few more dramatic ways we can give to someone else, in the spirit of that Cross, than to share our body and our blood” (20) –
makes clear that organ donation reflects Christ’s crucifixion not only in its compassionate desire to alleviate the suffering of strangers but in the flesh and blood sacrifice it entails. If, as Mongoven (2003) argues, Christ’s crucifixion is the supreme salvific act, and the donation of organs portrayed as a vivid imitation of this salvific sharing of the body, then “organ donation can be perceived as literal rather than symbolic eucharist, offering actual body and blood to give the power of life over death” (91). (See also Wilson 2000.)

Despite the directly drawn parallels between Christ’s compassionate surrender of his life for all sinners and the fleshy sacrifice of organs willingly proffered to strangers, the line between Christ in the first century and organ donors in the 21st century is not as straight as some Christians would have it. Religious ideas are influential but also historically and socially contingent. William Lafleur’s (2002) scholarship illuminates the particular social contexts and historical trajectories that married agape and organ transplant in the 20th century.

The mid-20th century, Lafleur (2002, 629) notes, occasioned a series of Christian revisions of traditional concerns for bodily integrity. The Southern Baptist Convention declared that complete resurrection of the body does not depend on bodily wholeness at death. Cremation for Catholics, forbidden in 1886, becomes permissible in 1963. A conflation of medical technologies at mid-century make measuring the body’s vital signs more exacting and convince some religious authorities to cede over to medicine whole territories previously considered religion’s. In 1958 Pope Pius XII declares in “The Prolongation of Life” that the determining point of death was a matter not for the church but for the physician. Changing attitudes to bodily integrity were not uniformly,
unanimously or wholly incorporated by Christians, but these revisions mark a new openness in the middle of the century to the non-necessity of bodily integrity at death.

However much changing religious attitudes toward death pave the way for organ transplant, they don’t dictate religion’s embrace of transplant, Lafleur notes (2002, 630). The 1950s and 60s were an exceptional time in the history of modern theology, Lafleur argues, and the Christian support for organ donation can be traced to the theological exposition of agape as the penultimate Christian value. Lafleur points to Anders Nygren’s phenomenally influential work *Agape and Eros* (published in 1930, translated and popularized in 1957), which tracked the two variant expressions of love in the Christian tradition and gave the name agape to the more amorphous, impersonal yet uniquely Christian mode of love. “Nygren’s work so effectively posed issues about love that they have had a prominence in theology and ethics they have never had before” Lafleur quotes one Nygren scholar (Outka as quoted in Lafleur 2002, 630). Agape emerges in this period as the quintessence of Christianity.

However, it is the publications of Christian ethicist Joseph Fletcher in the 1960s and 70s, Lafleur recounts, which explicitly link agape to the donation of organs. Fletcher was keen to introduce the perspective of situational ethics to Christianity. In his estimation situational ethics required a large dollop of utilitarianism. Utilitarian perspectives and values meant a firm commitment to avoiding waste and a reliance on agapic love as the best insurance of uniform, dispassionate and even-handed dispensation of justice. Fletcher even introduced an “agapic calculus” intent on achieving “the greatest amount of neighbor welfare for the largest number of neighbors possible” (Lafleur 2001, 637). In Fletcher’s view nurses and physicians were excellent examples
of agape translated into the routine of daily work. And the anonymous donation of cadaveric organs beautifully exemplified both the constructive use of here-to-fore squandered resources and the detached yet beneficent spirit of agapic love.

The allegiance, even devotion, of many Christians to organ transplant is a product, Lafleur (2001) argues, of these mid-century cultural currents: shifting attitudes to the body at death, a utilitarian abhorrence of waste, the elevation of agape as Christian love par excellence and a concern to implement theological concepts into social praxis. It is not a direct but a historically contingent route that makes Christ’s bodily sacrifice analogous to the donation of organs for transplant.

Dignified Bodies

So God created man in his own image, in the image of God he created him; male and female he created them.  

*Genesis 1:27*

No Christian assessment of organ transplant, even the most infatuated, strays too far from the notion that we are made in the image of God. Further, Christian doctrine holds that God became human in Jesus Christ and this central tenet likewise affirms the dignity of the human body. Catholic tradition, Teo (1992) states, “has always taken human embodiment seriously…such a position means the body has a special moral significance” (2114). There is widespread agreement among Christian commentators that organ transplant and donation must respect the body’s moral significance. This imperative is not, for the vast majority, a moratorium on organ transplant, but the measure of transplant policies and the limit to transplant possibilities.

If there is a single facet of organ transplant that Christian commentators agree on it is the currently legislated mandate of voluntary donation. “For Christians I have to say
the question of consent is very important,” stated Bishop Michael Nazir-Ali to the attendees of the Bradford Multi-Faith Conference on Organ Donation & Transplantation (2000). For the Bishop, and many other Christian commentators, donation should be made willingly, with full information, without undue pressure, and out of a spirit of altruism untarnished by motives of gain. Live donation by children or adults with learning difficulties should be carefully monitored. Deceased donation should continue to require the consent of donor and kin. In short, organs should continue to be gifts freely given.

What they cannot be, according to Christian dialogue, is commodities for sale. The body’s moral significance is such, Teo (1992) explained, “that it cannot be equated with other things or commodities” (2114). “Any procedure,” concurs Pope John Paul II (2000), “which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable”. So powerful is the notion that man is made in the image and likeness of God, writes an Orthodox theologian, “that the human being can in no way whatsoever be considered as a ‘laboratory rat’ nor as a breathing factory of living organs ready for transplantation for the sake, indeed, of commercial gain” (Viahos 1999, 147). For Christians the solution to long waiting lists and the suffering and death they represent cannot be a move to organ sales, tax incentives for donation or any other of a host of suggestions that imply a market for organs. (See also Wilson 2000, Anonymous 2000.)

Nor, for most Christian commentators, can the solution be “presumed consent”, a procurement strategy that has generated an increasingly vocal lobby. My review of Christian literature found no support of presumed consent (whereby all citizens are
presumed to wish to donate their organs upon death if medically feasible, unless they have previously declared their opposition to donation). It did, however, find a number of explicit rejections (see Clouse 1988; Bradford 2000; Pope John Paul II 2000; Ramsey 1970; Ebersole 1988). Verhey’s (2000) thoughtful article took note of the many ambiguities organ transplant raises: ambiguity in the determination of brain-death (and in the experience of death however defined), ambiguity in the relationship between persons and their mortal remains, ambiguity in relationships between donor and recipient. Given the ambiguities that surround organ transplant, ambiguities that religious resolutions alone cannot resolve, Verhey feels that the gifting remains the soundest moral approach. Presumed consent makes a lie of the gift relationship, it risks “violating the communal integrity of those who are ‘members one of another’ before they are members of the state”. And what presumed consent puts at risk, “creating a market in organs simply violates” (2000, 161).10

Christian commentators also used the inherent dignity of the human body to prescribe, with great uniformity, unconditional and non-discriminatory distribution of organs (see Wilson 2000, Nazir-Ali 2000, Pope John Paul II 2000). Hamel’s (1997) is a good summation:

Human beings are made in the image and likeness of God and therefore have a transcendent and inalienable dignity; we cannot deny someone an equal opportunity for an organ transplant on the basis of merit or social-worth considerations. (Hamel 1997, 19)

The question of equitable distribution of organs has been notably explored by ethicist and religious scholar James Childress (2001, 1991). His work makes clear the complexity of this issue (see also Mongoven 2003). The factors evaluated in the distribution of organs include medical urgency, probability of success, time on the list, and logistics of delivery.
Public policy in both the U.S. and Canada has prioritized these factors differently at different times and the weighting of each factor carries its own debate. Nor, as Childress (2001) points out, can such “medical decisions” be entirely free from bias.

An official at the Trillium Gift of Life Network, Ontario’s organ procurement organization, told me that the “ischemic times” (the amount of time organs can be held outside the donor prior to transplantation) were highly significant to their allocation decisions. Given the importance Ontario gives to transplanting organs with minimal delay, organs are not routinely transported across the province to the next person on the list but generally transplanted at a centre close to the procuring hospital.\(^\text{11}\)

When I mentioned the emphasis on ischemic times to an official at Quebec’s organ procurement organization, he was incredulous. “That’s crap”, he told me. Transport between any two places in the province is likely capped at two hours, he volunteered, and even for the most sensitive organs [heart, lung] this does not threaten the success of the transplant. Further, he added, kidneys (the most common transplant) have extended ischemic times that are even less likely to be affected by province wide distribution.

My interview with the TGLN representative suggested that the official knew full well why such emphasis was placed on ischemic times, although they were hesitant to openly declare it. In Ontario, for at least two decades, transplant hospitals have had well-established procurement ‘catchment’ areas and institutional ‘lists’ of waiting patients which they have guarded rather jealously as it ensures the continuing viability of their own programs. The formation of the TGLN was in part a provincial desire to mandate centralized waiting lists and province wide sharing of organs. Centralization, the TGLN
official told me, was “sensitive” and, if attempted, would have to be done “very strategically”. The TGLN representative was certainly cognizant of the fact that a renal patient waiting for a kidney transplant in Kingston, Ontario might wait a year or two while a renal patient in Toronto might wait five to seven years. This, they said, was “unfair” but addressing the underlying causes – a primary one, in my view, the reluctance of Ontario transplant centres to move to a centralized system of organ distribution and their reliance on the medical criteria of “ischemic time” to resist such a move – “was politically sensitive”.12

It is clear that medical criteria are not wholly impartial and, Childress (2001) also points out, social worth criteria still enter into the allocation of organs. In the early years of organ transplant social worth factors were explicitly considered. Stiller (1990) considers a 1968 study of kidney transplants done in Montreal that showed “male recipients significantly outnumbered female recipients”. He hypothesizes that

because men were considered the breadwinners in families, they were pushed ahead on the list. And since dialysis units were scarce, first priority was given to those patients most likely to show measurable benefit to society by returning to work and paying taxes. (1990, 71)

Blatant discriminatory distribution is no longer allowed; however, assessments of age, social support network, life style, behaviour patterns and mental health are routinely part of the social worker’s assessment of transplant “candidacy”. These are perhaps very necessary assessments, but frequently it is would-be recipients from marginalized and vulnerable populations that risk being disqualified. And in the U.S., as Childress (1991, 2001) notes, the ability to pay, the so-called “green screen”, remains a serious barrier to equitable distribution of extra-renal organs.13
Further, these are only the issues of what Childress terms “micro-allocation”. Organs are only one component of a compendium of health resources. Examining the relationship of organs to the macro-allocation of health resources generates a whole new series of questions (see Childress 2001; Mongoven 2003; Girod 2001; Hamel 1997).

The ethics of organ distribution and allocation is detailed and complex. Arguments about the dignity of the body and equal access to organs will not speak to every aspect of the debate. However, while the dignity of the body may be insufficient to decide the moral relevance of factors such as ischemic time or social support networks, it remains for Christians a staunch defence against morally irrelevant criteria such as race and sex.\textsuperscript{14}

**Embodied souls**

May the God of peace himself sanctify you wholly; and may your spirit and soul and body be kept sound and blameless at the coming of our Lord Jesus Christ.

\textit{I Thessalonians 5:23}

Twentieth-century Christians have described the body as both useful and dignified. They have also described it as intimately and irrevocably tied to the person or the soul. It is this link between body and soul that has most troubled Christian considerations of organ donation and transplant. From the early writings of Jewish philosopher Hans Jonas (1974) and Christian ethicist Paul Ramsey (1970) to commentators of the last two decades, Christians have wrestled with the implications of transplant technologies for the embodied soul.

Jonas’ (1974) concerns centred on the newly created definition of brain-death. He worried about the motivations of the new definition, “conveniently” arrived at to allow
the extraction of organs, and he worried about the “soul-body dualism” that the definition encouraged.

I see lurking behind the proposed definition of death…a curious reinvention of the old soul-body dualism. Its new apparition is the dualism of brain and body… Thus, when the brain dies, it is as when the soul departed: what is left are ‘mortal remains’. (1974, 139)

Against such dualism, Jonas emphasized the union of body and soul, or body and person: “My identity is the identity of the whole organism, even if the higher functions of personhood are seated in the brain” (1974, 139).

It is this same non-dualistic understanding of human persons that Paul Ramsey (1970) was intent to defend. Ramsey cautioned against a Catholic theology that would stretch traditional understandings of ‘totality’ to encompass the psychic and spiritual such that totality might be rewritten as “moral wholeness” (167) and that organ donation might be validated as actually seeking one’s own good, albeit a “higher order” of spiritual or moral good. Championing organ donation on the basis of an expanded totality caught up in notions of “man’s final membership one with another and with God in a rimless communion” (177) was a theological quagmire, Ramsey insisted. Protestant endorsements of organ donation that draw on agape are equally insufficient, Ramsey argued, if they are not consciously grounded in awareness of embodiment. Endorsing donation in pursuit of a “rimless community” or “untrammelled service of his neighbour” will “simply baptize the Cartesian mentalism and dualism of mind (soul, person) and body that is endemic to the modern mentality and an epidemic afflicting almost all contemporary outlooks” (193). Physicians should remain Hebrews, Ramsey states (193). They should scrutinize closely the dangers to the donor and the benefits to the recipient. “Charity” needs to be conceived “as the action of creaturely men, of men of flesh, and not
as the action of disembodied spirits” (Ramsey 1970, 195). Ramsey is somewhat unique in positing physicians as defenders of the body/soul union and religious traditions as forces of erosion if they proceed without the realization that the proper Christian understanding of persons is a fleshy one.

Both Jonas and Ramsey wrote when organ transplant was in its infancy, but their concern that brain-death and organ donation were potentially damaging to an embodied understanding of person echoes in contemporary Christian conversations. “If we learn to regard our bodies simply as collections of organs useful to others”, Meilaendar (1996) writes,

we are in danger of losing any close connection between the person and the body. That connection has always been affirmed in Christian thought, although it has often been a fragile connection… Having set foot on the path of transplantation, we seem unable to find any exit ramp as we press toward a vision of humanity in which everyone becomes ‘a useful precadaver’. (36, 37)

“Our rhetoric has generally favoured organ donation,” states Meiliendar (1996), but given Christian commitment to the connection between body and person, “we must learn to be circumspect in the use of such rhetoric” (33).

Further, while all Christians would presumably assert the union of body and soul in the living, the dead body is a different entity. Christian uncertainty about the nature of the corpse is frequently no more than alluded to (see Wilson 2000, Teo 1992), but Verhey (2000) eloquently captures some of the ambivalence:

To be sure, because persons may not be reduced to their bodies, there is a discontinuity between persons and their mortal remains. But because persons may not be reduced to minds or ghosts or disembodied souls, there is also continuity between persons and their mortal remains. Continuity helps us understand refusals to donation, grossness of being in an anatomy lab, horror at dismemberment. Discontinuity helps us to understand how medical students can settle down to tasks
of learning parts and functions, and how family and friends experience in the presence of mortal remains that the one they loved is somehow gone (157).

It is precisely Christian recognition of the discontinuity between persons and their mortal remains that permits organ transplant and precisely Christian recognition of the continuity between persons and their mortal remains that problematizes it. Verhey reminds us that while the union of the body and soul might indeed be challenged by new definitions of death and technologies of transplant, the very event of death challenges this bond. In Christian doctrine, bodily resurrection has traditionally been the assurance of the continued integrity of body and soul beyond death. If Christians have found transplant a challenge to the embodied souls of the living, it is not surprising that transplant has impacted Christian understandings of the resurrected bodies of the dead.

**Resurrected Bodies**

But some one will ask, “How are the dead raised? With what kind of body do they come?” You foolish man! What you sow does not come to life unless it dies. And what you sow is not the body which is to be, but a bare kernel, perhaps of wheat or of some other grain. But God gives it a body as he has chosen, and to each kind of seed its own body. I Corinthians 15:35-38

Refusing or resisting the donation of organs for fear of jeopardizing the Christian promise of bodily resurrection seems a slightly disreputable, antiquated or eccentric belief – nobody in the literature I reviewed admitted to having such a view but everybody seemed to know someone who did. Christian commentary on their subterranean brothers and sisters was of two minds. Some, primarily theologians, took care to advise the “misguided” of the doctrinal compatibility of organ donation and resurrection. Others, primarily ethicists, defended the religious validity of resurrection theology at odds with organ donation and stressed the complex ways doctrine becomes contextualized in
people’s lives. Their position is summed up in the comment of scholar of religion William Lafleur (2002): “any idea of resurrection is a ‘religious’ idea and should be met on religious grounds” (629).

Given that the Christian tradition has been responsible for “an overemphasis on the resurrection of the physical body”, Ebersole (1988, 111) felt justified in calling for Christians, individually and collectively, to re-examine this tenet of their faith. “What do you believe about the resurrection of persons? How has this belief influenced your attitudes toward donating your organs for transplant” he would have them ask. “If necessary,” he directs them, “spend some time looking at what the Scriptures say about the body and resurrection” (112). Ebersole’s directives are rather open-ended, but some Christian ‘correctives’ are considerably more explicit.

To dispel the idea that organ donation interferes with the bodily resurrection, Simcox (1986) offers four theological defences. First, love and charity are the Christian virtues that “result” in resurrection; organ donation is in keeping with these. ‘He who loses his life for my sake shall find it’, Simcox quotes and adds, “Our concept of resurrection must be grounded in the Lord’s promise that those who give their lives in obedience to God in love for others, keep—find—their lives forever” (200). Secondly, God can overcome any challenge to the resurrection of the body and will not be “stymied” by “missing livers”. Third, we are not privileged to know the exact nature of the risen body; its relation to our present body is one of similitude not duplication. “Our resurrected body will be our present body in fruition, like an oak tree is an acorn in fruition” (200). And lastly, science and medicine have made clear the cellular processes
of renewal and replacement that are constantly at work in the body. This too, claims Simcox, is “resurrection”:

At every second, really, God is giving us a new body, for any body that is infinitesimally different from the body of a minute ago is a new body. We are normally unconscious of this constant renewal and piecemeal replacement of ourselves, but the truth is that when we got up this morning we got up into a body designed for today. We will get another new one tomorrow; we are getting a new one now. And this is resurrection – slow, silent, constant resurrection. (201)

To rewrite the triumphant event of the Christian resurrection of the body as a process of constant flux and change is thoroughly post-modern theology. It parallels, in many respects, the Christian acceptance of death as a process of disintegration and disorganization best charted by physicians rather than a singular cessation best watched over by clerics. Contemporary Christian attitudes to death, note several scholars, emphasize the continuity of the soul rather than the resurrection of the body (Walter 1996; Prothero 2001; Lawrence 1998). But Simcox’s (1986) reframing of the resurrection suggests that the body is not discarded from Christian constructions of the afterlife. In keeping with recent scientific and philosophic understandings, it is re- visioned as an open, evolving potentiality rather than a solid and familiar entity (see also Clouse 1988, 19). The flexible boundaries and horizons of this body are compatible with both organ donation and resurrection.

But not every Christian is post-modern. Mongoven (2003) claims there are “numerous Christians of multiple denominations who reject donation because they believe organs will be needed in a resurrected body” (101). Sanders (1995) notes how prevalent these beliefs are among African-American Christians and suggests their allegiance to bodily integrity at death is rooted not only in Christian doctrine but also in African traditional religion which attributes sacredness to the human body and to the least
of its parts (146). In addition, black religious beliefs unsympathetic to organ donation are reinforced by black experiences of prejudice and racism in the delivery of medicine and the attitudes of its practitioners, Sanders argues. To cultivate organ donation among African-Americans, culturally sensitive approaches are needed. And no approach, Sanders cautions, will eradicate resistance: “organ donation requires that life-and-death decisions be made in the shadow of profound uncertainties in religion, ethics, and medicine” (1995, 152).

Had it not been for a telling moment in my own research, I might have been tempted to locate unease about organ donation and bodily resurrection where Christian commentators have most frequently found it – in ethnic minorities, in less dominant Christian denominations or in “fundamentalist sects” (Ebersole 1988, 107). But the troubled confession of a mainstream Christian and long-time soldier for the Kidney Foundation suggest that the bodily resurrection is an unspoken stumbling block impacting any number of Christians considering organ donation.

I had attended a “Celebration of Life”, a ceremony honouring dialysis patients, kidney recipients and their donors, hosted by a branch of the Kidney Foundation in a small city in southern Ontario. Vivian, the organizer of the ceremony, had agreed to be interviewed about the history, intention and dynamics of this rite. Vivian and her colleague Lois, who managed fund-raising efforts for the branch, kindly treated me to lunch at a nearby restaurant before we began the interview. Both Vivian and Lois are long time employees of the Kidney Foundation, both are middle aged women with adult responsibilities (Vivian was caring for her ailing father, Lois had three children attending university), both are practising Christians. Our lunch was a comfortable, talkative affair
with many stories about the kidney recipients and the dramatic impact of transplant on their lives, and many emotive accounts of kidney donation, both live and deceased. I told them briefly about the aims of my project and the relationships I saw between organ transplant and religion.

Vivian and I held a formal interview in her office after lunch. Preparing to leave, I stuck my head in Lois’ office to say good-bye. “Do you have a minute?” Lois asked. She wanted to know more about my study of religion and organ transplant. Vivian was nearby at the photocopier, and I explained to them the various ways I thought transplant and religion intersected. I was rather pleased that of all the myriad directions our conversation had gone at lunchtime, the relationship between religion and transplant seemed to have captured Lois.

But Lois’ pondering about religion and transplant considerably pre-dated our lunch. When Vivian was called away to the front office, Lois confided her dilemma. She knew that Christianity endorsed organ donation, she told me. In fact, she and Vivian had attended a talk at a Catholic church where the Father had given a very positive appraisal of organ donation and transplant. It was held at her childhood church; her mother still attended there. But memories of her religious upbringing competed with the Father’s words, leaving the issue of religion and transplant unresolved for her.

When I was a girl, I can remember there was a child who had been hurt, killed in an accident, and missing a limb; it had been severed. And I can remember the limb was buried in the gravesite, it was reserved for the person when they died. You know -- so that the body could be in one place, ready for the resurrection, ready to be made whole again. And I know that isn’t done anymore, it doesn’t matter where your limbs are, and that’s why the Church can get behind organ transplant.

But I can’t shake it, you know, this outlook I was raised with. And I worry about it a bit. In fact, when I think about it, having the body all collected and whole and waiting for the resurrection, then I’m not 100% sure about my feelings for
transplant. Imagine me, working here and feeling that! I’m still for transplant. But in my case I was a smoker up until fairly recently, so I know they wouldn’t want my organs, so that’s kind of my way out.

Vivian, she doesn’t worry at all about this. She told me she believes we get a new body when we die and are resurrected. That’d be nice -- we wouldn’t mind an improvement on these ones! Vivian’s hoping for Jayne Mansfield! But I’m…not so sure that that is what happens.

Lois’ account captures several aspects of the complex dynamic of organ transplant and bodily resurrection. Unspoken at the church, unspoken at lunch, and unspoken until her friend and colleague left the room, Lois’ concern for bodies buried without organs is private. Estimates of Christian resistance to organ donation based on concern for the bodily resurrection should take this into account. It would appear that Christians from mainstream denominations, especially when they are aware of denominational support for transplant, do not feel free to voice their misgivings about resurrection and organ donation. Embedded in vivid memories of death, grief and ritual practice, impressions of the bodily resurrection will not easily be overturned with reassurances of the Church’s ‘new understanding’, not even when delivered by recognized figures of clerical authority.

But Lois’ narrative also underscores how deeply individual constructions of body and resurrection are. Two women of similar age, ethnicity, occupation and religious background have arrived at two strikingly different evaluations of the body after death. Both highly sympathetic to victims of organ failure, Vivian’s confident anticipation of her new body lends itself easily to technologies of transplant; Lois’ concern for the one she was born into troubles her participation in those same technologies.

The individual nature of such constructions, born out of the minutiae of particular lives as much as the injunctions of religious and cultural traditions, should make clear
that broad admonishments about *either* the malleable or steadfast nature of our ensouled bodies are insufficient. If a human person is constituted by some intricate weave of body and soul, as Christians generally insist, then this bodily integrity also insinuates some sort of personal sovereignty. Bodies shape souls, and souls then declare what bodies mean and what they are. The relationship is reciprocal and highly personal. It is precisely this sort of agency and autonomy that one Christian ethicist would have us consider in her unique assessment of organ transplant as analogous to pregnancy.

In Jung’s (2001) view organ transplant and pregnancy are comparable because both require us to lend our bodily support to others in need. Because of the body’s integral relation to person such bodily support can never be mandated, Jung argues (maintaining the voluntary status of organ donation and the legality of abortion). However, Christian vision implies the willingness of integral and sovereign body/persons to accept servanthood in support “of all those who come crashing into our lives in need of the fullness of our bodily support” (Jung 2001, 292).

There are those ‘oughts’ which stem from other visions of communal life… Those ‘oughts’ are best thought of as self-imposed by the self’s desire to be in its fullness a certain kind of person and to create a certain kind of community. (Jung 2001, 282)

As Christian feminists have pointed out, such visions can constitute “servitude” rather than “servanthood”, especially for women, Jung allows. However, pregnancy and organ donation do not inherently constitute either. The lending of bodily support to those in need becomes either the fulfillment or the degradation of Christian vision as it is worked out in individual desires, memories, conditions and circumstances. Bodily integrity, Jung argues, presumes the agency of each body/person to assess the limits
and the extensions of this union in harmony with Christian vision and in keeping with their particular lives.

Communal Bodies

For by one Spirit we were all baptized into one body -- Jews or Greeks, slaves or free -- and all were made to drink of one Spirit.

*1 Corinthians 12:13*

Lois’ narrative also reminds us that we cannot conceptualize the individual body/person in absentia from all the bodies and persons that entangle us. Our experiences of body and person, and our projections of self after death, are kneaded by the press and pull of those bodies around us, the bodies of those we love, and even the voluptuous curves of a Hollywood film star or the mangled limbs of a neighbourhood child. Transplant engages the communal body.

Christian literature on transplant frequently stressed the collective benefit of donating organs. “An act of organ donation thus becomes an act of human solidarity serving the common good…and all of this in stark contrast to a world so obsessed with selfish individualism”, said Fr. John Wilson (2000). “Transplant, uniquely, has the capacity to bring a community closer, and to promote international goodwill among peoples”, concurs Teo (1992, 2114). And Allen Verhey (2000) believes that framing organ transplant in Christian understanding and ritual could eliminate perceptions of organ donors and recipients as locked in a creditor-debtor relationship for “they are both recipients, bound together by the common indebtedness to God, and giving and sharing are mere tokens of community” (167).
The danger in making organs the tonic for communal bodies, some Christian ethicists caution, is that “we will see a growing tendency to think of cadaver organs as communal resources available for the taking” (Meilaendar 1996, 36). Refusal to donate, Mongoven (2000) cautions, is all too frequently assessed as uncivil or irresponsible. Religious halos around “rimless communities”, enjoins Ramsay (1970), give not enough heft to the fleshy human person.

What Christians think about organ transplant, at least those Christians speaking in sectarian journals and ethics publications, derives from and speaks to core elements of the Christian faith. Christians use transplant to enjoin the sanctity of life, invoking alternately the lengths needed to protect it and the limits curtailing its extension. Transplant discussion encompasses Christian respect for the beginning and the end of life and the proper role of science in shaping these passages. Christians use organ transplant to update Christ’s life, passion and resurrection into post-modern understandings and contemporary technologies. And, centrally, Christians debate organ transplant to refine their understanding of human bodies, persons and communities and to accentuate the wisdom and humility needed to ascertain the correct balance between them.

There are limitations, even in the extensive discussions that exist. There is a tendency to focus on cadaveric donation at the expense of fuller treatments of the ethics and theology of live donation. The centrality of Christ’s death and resurrection to the meaning of organ donation and transplant predisposes Christian commentary to emphasize cadaveric donation, despite the large and growing number of live
donations. The theology and experience of receiving an organ is also given short shrift in the Christian literature. In my review I found only two articles written from the perspective of a Christian recipient (Clouse 1988, Hughes 1980) and even one of those noted “very little bioethical reflection has been done from the standpoint of the patient” (Hughes 1980, 367).

If there is Christian consensus about organ transplant it is on issues of social policy. Organ donation should remain voluntary with neither the state nor the market allowed to circumscribe the “gift” of organs. Complete and irreversible cessation of the whole brain should remain the standard for designating death, and organs should not be procured from vulnerable populations on the edges of death. Allocation of organs should be unbiased and unconditional, but alert to the complex ethics of ‘fair’ distribution.

If there are attitudes or inclinations attributable to certain Christian populations they are tenuous at best. Articles in the evangelical publication, Christianity Today, had a tendency to be ‘issue-driven’, to centre their reflection on particular biotechnologies or moral questions: donation from anaencephalic infants, abortion, stem-cell research. Articles in the liberal Protestant publication, Christian Century, were sometimes larger in scope, tying organ transplant to questions of identity, death or biomedicine more generally. Christian ethicists positioned themselves between theological and academic worlds and their work tended to be more nuanced and to intersect with other scholarly discussions. Nevertheless, Christian ethicists amply demonstrate that careful, balanced treatments of theology and transplant can be either
celebratory or cautionary as Ebersole (1988) and Meilaender (2000) show or as the

Whatever the tendencies, there is no consensus on what organ transplant
“means” (and what it can and should mean) to Christians. To say, as organ
procurement organizations are wont to do, that “all major religions support this act of
charity and consider it a beautiful gift”, is not so much a sin of commission – although
there are Christian sects on record as non-supportive – as it is a sin of omission. Such
a statement fails utterly to give any sense of the lively debate, serious caveats, multiple
meanings, pronounced cautions and silent misgivings that punctuate Christian
elaborations and endorsements of organ transplant.

Are public officials brazenly repeating a bald lie? Certainly they are
contesting the characteristics and contents of religion in ways that belie scholarly
assertions that ‘religion’ is primarily an academic construct used to further disciplinary
debates and boundaries (see McCutcheon 1997, Fitzgerald 2000). Perhaps it is not so
much pathological psychology that perpetuates the public stereotype of straight-
forward Christian assent to organ transplant as it is the rather narrow definition of
religion that transplant officials adhere to. In the copious distribution of sectarian
resolutions in favour of organ transplant, in the diligent listing of religious ‘beliefs’
about transplant, in the courting of religious officials and in the assurances that ‘all’
religions are very much ‘the same’ when it comes to organ transplant, organ
procurement officials and other transplant advocates are working from common and
pervasive assumptions about religion that fall apart upon examination. The
assumptions? That sectarian officials ‘direct’ religious behaviour and can ‘represent’
a faith tradition. That religion is mostly about belief. That religion is wholly positive and faith traditions – since they are all pursuing morality and good will – mostly interchangeable. That religion can be neatly severed from science, economics, ethnicity, philosophy and other arenas of culture. That religion is consistent and comprehensible and internal conflict can be resolved by appealing to the ‘highest’ authority.

Even at the level of theological discussion, as the preceding hopefully demonstrates, such generalizations do not hold. Christianity proves contentious, paradoxical and full of opinionated voices with and without official standing.

Christian reflection on transplant is invested with beliefs, but also weighted by rituals, captured by visions and haunted by experiences. Christians assess organ transplant with reference to Jesus and to scripture, but these assessments cannot escape contemporary arguments about philosophy, theology, ethics, science, race and recycling – to name just a few.

If the tidy numeric entries on the Chinese menu dissolve when Christianity is really digested, how much more impossible it is to assess religious individuals, and in particular the spirituality of transplant recipients, with a series of check boxes. In the chapters that follow it is the untidy, intricate, lived religion of organ recipients that I wish to explore.

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1 The journals *Christianity Today* and *Christian Century* featured a spate of organ transplant articles in these two decades and are the core of this review. See appendix 1 for further details on these two journals and consideration of the other journals and articles included in the literature review.

2 In this respect my review of Christian literature differs substantially from the literature review conducted by The Canadian Council for Donation and Transplantation (2006). Their findings primarily consider whether faith groups support, accept, are neutral or against organ transplant (2006, 4). Further, I was not trying to discover what faith groups “officially” believe, a key concern of the CCDT review. The CCDT
review restricted itself to “quality” articles -- research studies or articles with a significant number of references (2006, 3). Not surprisingly, their bibliography is almost entirely comprised of articles published in medical journals and websites sponsored by transplant advocacy organizations.

3 Canada’s 2003 deceased donor rate was 13.5 per million population, a rate that has been stagnant over the past 10 years. (Canadian Institute for Health Information, http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=reports_corrinsites_apr2005_trends_e). A 2006 report by Dr. Lilyanna Trpeski, senior analyst for CORR, demonstrates the low donation rates amongst Canada’s ethnic populations (http://www.transplant.ca/downloads/Trpeski%20-CORR%20Update.ppt#1).

4 In February 2006, the Ontario government was presented with a private member’s bill advocating presumed consent be passed into law. The bill did not pass but it did stimulate a second private member’s bill designating “Mandatory Declaration” in Ontario (Bill 67, 2007), which would require all persons of 16 years of age to specify on their health card or driver’s licence what uses are to be made of the person’s organs or tissue after death or to specify that the person is undecided. This bill reached the Standing Committee on Social Policy, but died before third reading when the legislature was prorogued.

5 A notable exception in Ontario is Rabbi Reuven Bulka. Rabbi Bulka is the Rabbi of Congregation Machzikei Hadas of Ottawa. He is also Chair of the Organ Donation Committee of the Kidney Foundation of Canada, Eastern Ontario Branch and sits on several government committees examining organ and tissue donation issues. Rabbi Bulka has published and lectured on organ donation, and the religious and ethical aspects of donation and transplantation. He frequently promotes organ donation at his temple and through his weekly radio show.

6 http://www.transweb.org/qa/qa_txp/faq_religion.html [created 2003, accessed 01/22/05]
7 http://www.hc-sc.gc.ca/english/organandtissue/my_religion/index.html [created 07/16/02, accessed 01/22/05.]
8 The bioethics titles and details about codes of medical ethics are gleaned from Walters (1999). This trajectory of concern is confirmed in Verhey (1996, 1-3). The role of religion in this bioethics ‘revival’ is explored in Smith (1996).

9 The long standing ban on federal funding was partially lifted in 2001 when President Bush allowed for federal funding on existing stem cell lines. U.S. legislation, however, banned the creation of new stem cell lines that would require destruction of an embryo. Newly elected President Barack Obama signed an executive order in March 2009 that lifted Bush’s restrictions on this research. In Canada the Assisted Human Reproduction Act became law in 2004. It prohibits human cloning (including therapeutic) and all commercial production of or transactions in reproductive materials. It does allow, under licensed conditions, stem cell research on embryos left over from fertility treatments.

10 If the market and the state are not acceptable sources for organs because of the dignity of the body, several Christian commentators were emphatic that animals were an unacceptable source for the same reason. Xenotransplantation, according to Vaux (1984) transgresses “a certain kind of human wholeness” (1144). Even more succinct is an Anglican commentator (Beresford 2000) who claimed that the “yuck factor” in xenotransplants ought to be heeded. (See also Nazir-Ali 2000.)

11 Donated organs are allocated first to “high status” transplant candidates, i.e. death imminent, if they are compatible. Procurement personnel, according to this TGLN representative, have a nation-wide list of high status patients and organs for these patients are shared across the country. However, if there is no compatible high status recipient, Ontario’s donated organs go to patients in the region that procured the organ.

12 The political sensitivity referred not only to the territorial interests of transplant centers, but also to issues of ethnicity. Asians have a predilection for kidney failure and wait times in Toronto are exacerbated by the large Asian population. This interview took place in 2003. By 2005 TGLN was reporting that they had assumed province wide responsibility for coordinating and allocating organs from deceased donors (http://www.giftoflife.on.ca/assets/pdfs/AnnualReport0506ENG.pdf). Federally, however, organ procurement and distribution remains fragmented, see Kondro (2006), although this may change with the August 2008 designation of Canadian Blood Services as the national coordinator for organ transplant and donation.

13 In the States Medicare covers dialysis and kidney transplants but offers spotty coverage for other organs and for drug coverage, covering only 1 year post kidney transplant. Much of the decision to fund or not
fund extra-renal transplants falls to the individual states. In Canada all transplants are publicly funded. Most provinces have provincial drug plans if the recipient does not have adequate private insurance to cover requisite medications.

14 I am indebted to Childress’ (2001) distinction between morally relevant and irrelevant criteria.

15 nowhere is this more evident than in Mongoven’s (2003) exclusion of live donors from her examination of the Christian dynamics of “sacrifice” in organ transplant
I think people’s walk through life, it can take you many places and it can make you run to the farthest corner, as far away from God as you can get because you’re so angry with him… But I think some people’s brings them to a very special place, with God. And thinking how many times you should’ve been dead and you’re still here, and maybe you better start working on finding out why.

- Theresa, kidney transplant recipient

Death is a pervasive topic in the literature on organ transplant. Statisticians record how many have died waiting for transplant and calculate the death rates of recipients to gauge the success of each transplantable organ. Legislators encode new definitions of death to facilitate transplant while ethicists and anthropologists grapple with this new brain-death (see Jonas, 1974; Lock, 2002). Hospitals establish protocols to determine treatment of the newly dead and almost dead that scholars then assess and debate (see particularly the controversies over non-heart-beating cadavers, Arnold, 1995). Religious leaders consider how organ donation challenges or corresponds to traditional views of the body at death. This chapter likewise engages the subject of death and transplant. But its focus is not death as a fait accompli, but death postponed; it argues that the averted death of organ recipients is a central site for the production of religious meaning.

As with the scholarly literature, death was a pervasive topic in the interviews that I conducted with organ transplant recipients. Participants narrated to me the death of parents and spouses and friends, funerals and memorials they’d been to, speculations on their deceased donor, rituals of remembrance they performed, and centrally, and without exception, their own close encounter with death. As kidney recipient Teresa says in the quote at the beginning of this chapter, “thinking how many times you should have been
dead and you’re still here” was for many an imperative to “start to find out why”. This ‘finding’ had both a ritual and a discursive dimension, both a this worldly and an other-worldly orientation. It was prompted both by the reflective recognition that they “should have been dead” and by the embodied experience of being close to death.

Recipients’ experience, recognition, ritualization and pondering of death is the central theme of this chapter. Transplant does not solve the problem of death. To be sure, recipients are very glad they are not dead; but they are also very aware of their own mortality. Contrary to many scholars who see transplant technologies evincing a modern denial of death, I argue that the immortality organ recipients seek is not a simple hunger to live longer. I describe the recipients under study as “spiritual seekers” traversing a particular early 21st century terrain shaped by the practices and discourses of what Foucault (1976) termed ‘biopower’: a desire “to ensure, sustain, and multiply life” (138), a novel force of propulsion proceeding through the discipline of the body, the regulation of populations and the semi-autonomous modifications of the self.

It is possible to view the active agenda to foster life as a kind of immortality quest. But the pursuit of immortality has always been replete with moral and theological correlates; this caveat is also true of the tenuous life extension granted by organ transplant. The moral correlate to biopower’s “administration of life” is, according to social theorist Nikolas Rose, a “novel somatic ethics with obligations as well as hope” (2007, 8). I discuss the “somatic ethic” as it transpired in organ recipients’ determination to live ‘fully’, yet responsibly, in the awareness of death and in communion with others so afflicted. Recipient’s attempts to “find out” what their survival insinuated also yielded novel articulations of life after death. I argue that the celestial imaginary they articulated
resurrected souls, angelic gift givers, scattered organs and a continuing communion between the living and the dead – is a cosmology that carries the optimization of life beyond death.

Finally, I turn to a discussion of transplant’s modes of exchange, revisiting the ongoing debate about gifts and commodities in organ transfer. Transplant’s ability to generate life from the bodies of the dead has sparked heated debate about the nature and portent of this exchange. Transplant scholarship tends to castigate the rhetoric of the gift, claiming it a mask for the commodification of the body. However, I believe the rhetoric of the gift demonstrates Rose’s argument (2007) that the new biological values taking shape are simultaneously ethical and commercial. In the context of biopower, “the Gift” takes on very different meanings than Mauss’ classic articulation of the obligatory nature of gifts, their role in establishing and maintaining social relations, and their contradistinction to commodities.

*Contemporary Spiritual Seekers*

The recipients in my study, with only two exceptions, openly declared or clearly implied that the transplant experience touched their spiritual lives. A correlation between transplant and spirituality cannot be extrapolated to all organ recipients. Nevertheless, this group was articulate about the ways their new organ invoked the sacred: they described new metaphysical understandings, they spoke of a closer relationship with God, the universe and other human beings, and they divulged experiences of inexplicable emotional states, visions, presences or coincidences. Several of the participants in this study identified as Christians and almost all could be described as being of Christian
heritage; most used Christian tropes to describe their experiences or the conclusions they drew from them. However, it is not primarily their institutional religious life that I explore, but, more broadly, their “spirituality”.

I employ the term spiritual because my foci tend to coincide with the attributes of spirituality described by scholars of religion. Spirituality is said to highlight individual experience and consider it authoritative (Roof, 1999). Where practitioners differentiate religion and spirituality, they consider the latter to be “more personal, immediate and authentic sacrality” (Klassen, 2001, 65). Contemporary spirituality is enacted on a wide plane, not bounded by the walls of sacred institutions. It supersedes institutional loyalty, drawing from a “marketplace” of cultural resources – diverse traditions, political movements, psychology. Conversely, production of the spiritual feeds this self-same marketplace with new elaborations of the sacred and the practises best suited to engaging it (Roof 1999, Wuthnow 1998). In addition, I use the term spirituality to distinguish my interest in the “lived religion” (Hall, 1997) of embodied recipients from the typical scholarship on religion and transplant which emphasizes official, rather disembodied, doctrines, institutions, and actors (Keyes, 1991; O’Connell, 2001; Veatch, 2000).

Recently, Leigh Eric Schmidt (2005) has argued that the contemporary phenomenon of spiritual seeking has deep roots in the 19th century. Schmidt explores in detail the contributions of Transcendentalists, romantic Unitarians, Reform Jews, progressive Quakers, devout disciples of Emerson and Whitman, Spiritualists, questing psychologists, new Thought optimists, Vedantists and Theosophists to a socially progressive and religiously liberal alternative to mainstream Christianity. These seekers made mystical experience, meditative interiority, universality and a sympathetic
appreciation of all religions enduring hallmarks of the “spiritual” quest. “The now prevalent notion of being spiritual but not religious is itself primarily a seeker’s code for the rejection of exclusive salvation, moral correctness, and the institutional apparatus of conservative Christianity,” Schmidt writes (2005, xii).

“Rejection” is too strong a term to describe the relationship my participants had with institutional Christianity. But what becomes apparent in many recipient narratives is the inability of institutional Christianity to adequately embrace the gamut of experiences and emotions that accompany chronic illness and organ transplant. In a Christian culture that often prizes the stoic acceptance of pain (see Orsi, 1996), an admission of addiction to narcotics – not an unlikely scenario given her usage since childhood -- led to one recipient’s exclusion from her conservative church community. Another recipient described her frustration in finding a wheelchair accessible church for her wedding. She considered the Catholic Church to be unresponsive to the needs of her and her disabled partner because of long-standing and deep-seated misgivings about the marriage of disabled people -- especially those, like themselves, unable to procreate.

Christian ambivalence toward the bodies of the chronically ill is highlighted in its dual embrace and denial of the transplanted body (see Chapter 1). In conservative circles where transplant is most suspect, especially given its connection to fetal tissue research, one participant awaiting transplant recounted being counselled by members of his congregation “not to go through with it”, counsel that he vehemently rejected. Dean suffers from polycystic kidney disease, a genetic disease that killed his father at a young age, has attached him to a dialysis machine and now looms as a threat for his own son. Throughout the interview he stated and restated his belief that science would prevent his
reality from being his son’s. “There’ll be something a lot easier for him,” he reassured me (and himself), “either grow his own or get a baboon or a pig or something”. But when the conversation turned to stem cell research that could advance such possibilities the straightforward march of science became problematic. If the stem cells were harvested from a fetus aborted due to congenital defect or health risks to the mother, Dean was happy to see research proceed. However, “if it’s somebody that got careless and went out and got pregnant and they just want to abort it, that’s where I have a problem with that”, he stated. “But”, he added after a moment, reflecting the dilemma of being a conservative, evangelical Christian with a serious genetic illness that progressive science and research hold the keys to -- “nothing’s black and white, it really isn’t”.

Even in more liberal Christian settings where organ donation has been scripted as a postmodern path to Christian compassion and community, organ recipients do not always find solace – especially when their experience deviates from the script. George and Candice met in the pews of their United Church congregation; their religious lives and the support of a church community were important to both of them. Very early in their relationship, when Candice’s first transplanted kidney began to fail, George decided to donate his kidney to her. But the relationship broke up shortly after the transplant, the whirlwind romance unable to withstand the pressures of blended families, chronic illness and a donated organ. Candice found herself shunned by the community she had long been part of. “I thought these people were my friends,” she related, “and now I’m not so sure. And I haven’t really been [to church] for…a while. And almost no one has called me. And there’s been, there’s comments that I’ve taken advantage of him and, you know, all that.”
“If we had come out of the transplant intact, it would’ve been, ‘Oh, isn’t this wonderful!’ and ‘Praise the Lord!’ and ‘Great, great, great!’ But we didn’t. And they didn’t know what to do.”

It should not be inferred from these stories that organ recipients do not find meaning, support and comfort in institutional Christian settings. Many did, much of the time. Such stories are meant to suggest that there is both a novelty and an excess to the experience of transplant that is not always adequately reflected in institutional Christianity. Like Schmidt’s seekers of the 19th century, and in keeping with many sojourners of the 20th century, transplant recipients often feel compelled to search for a larger religious world.

While organ recipients eschew the meditative interiority that defined spirituality for the 19th century (the power and promise of the body, not the mind, takes priority with these seekers⁴), they nevertheless privilege other touchstones of an established “spiritual” tradition: a liberal assessment of religious authority, a keen sense of universal connection, and the primacy of immediate, often mystical, experience. In directing me to these elemental experiences, experiences which took place outside religious sanctuaries, experiences interpreted through multiple lenses and refracted in new found communities rather than official congregations, my participants pointed to the ‘spiritual’ component of transplant – and this is what they called it.

What makes the spirituality of this group particularly fascinating is the moral ambiguity of organ recipients. Recipients, echoed by organ donation advocacy groups and a large number of religious organizations, frequently assert that organ transplant
resurrects both body and spirit. But those less enamoured of transplant, religious and secular, claim that the exchange of organs is a threat to an integral, embodied understanding of person (Girod, 2002; Meilaender, 1996), a disregard for human limits (Fox & Swazey, 1978, 1992) and a hindrance to bodily resurrection (see accounts in Sanders, 1995). In various popular media the portrayals of organ transplant as a gift of life generously given are equally matched by stories of organs sold and organs snatched in sinister bids for life extension.

At the heart of the scholarly critique of organ transplant is an unshakeable conviction that the professional zeal to perform transplants, the public support for the technology and the anxious anticipation of would-be recipients stem from a misguided endeavour to resist death indefinitely and unnaturally. Medical sociologists Fox & Swazey (1992), whose two decades of field research is the cornerstone of social scientific study of organ transplant, wrote:

In our view, the field of organ replacement now epitomizes...our pervasive reluctance to accept the biological and human condition limits imposed by the aging process to which we are all subject and our ultimate mortality. It seems to us that much of the current replacement endeavors represent an obdurate, publicly theatricalized refusal to accept these limitations. (Fox & Swazey, 1992, 205)

Their stance is reaffirmed in subsequent scholarship. Meilleander (1996) considers transplant to partake of “our society’s desperate attempt to find ways to live longer” (37). Awaya is even more unequivocal, seeing “transplant surgery as a form of neo-cannibalism...we are now eyeing each other’s bodies greedily, as a source of detachable spare parts with which to extend our lives” (in Scheper-Hughes, 2000,198).

Medical anthropologist Margaret Lock (1995) concurs with the evaluation of transplant as a contemporary denial of death: “in a world...where death is dirty and everlasting
happiness is, it seems, one of our supreme goals...striving for immortality is unquestionably a laudable goal, just as resignation to death is a sign of weakness and defeat” (391). It is, she concludes, “the collective quest for immortality...that drives the transplant endeavour forward as though it were an entirely natural and rational enterprise” (393).⁵

Such aspersions seem shrill – and somewhat dated. Contemporary biotechnologies are not merely ‘flouting’ natural biological limits imposed by the aging process. Transplant, and other reproductive, genetic and neurochemical biotechnologies, are throwing into question the very categories and trajectories of “biology,” “nature” and “aging” (see also Haraway, 2004). “These new technologies, then, do not just seek to cure organic damage or disease, nor to enhance health, as in dietary and fitness regimens, but change what it is to be a biological organism” (Rose 2007, 17). Paul Rabinow (1996) claims that we have moved beyond socio-biology to biosociality -- biology is being “known and remade through technique and will finally become artificial...nature will be modeled on culture understood as practice” (100). Organ transplant is not an entirely natural enterprise. It is eminently artificial and accepted as such. It does not become ‘natural’ to have three kidneys; however, it does become conventional to presume human physiology alterable. Biology is no longer blind destiny, claim Nikolas Rose and Carlos Novas (2005), “it is knowable, mutable, improvable, eminently manipulable” (5).

To denaturalize biology and release it from destiny inculcates a whole series of “strivings” and key among them is the optimization of health. And, as the transplant scholars charge, such striving is seen as laudable. The optimization of health is the purview of active citizens: “ignorance, resignation and hopelessness in the face of the
future is deprecated” (Rose & Novas 2005, 6). However, the dissolution of nature, the artificiality of biology, suggests that such strivings, while celebrated, cannot be cast as human hubris or triumphalism. There is no ‘natural’ limit to conquer and no place beyond that limit where striving might cease. Indeed, it is likely the commitment to striving, rather than the prize of immortality, that fuels this particular “political economy of hope” (Rose & Novas 2005, 5). Further, as Rose and Novas point out, the transparency of genetic futures and the acceleration of health-related decisions and responsibilities produce as much anxiety and dread as they do hope (6). Even its proponents know that every move to optimize health builds a chain of interrelated dilemmas and possibilities, not a highway to everlasting happiness.

Various scholars also note that there is a collectivizing moment to the forces that Foucault designated as biopower, or that Rose refers to as “the politics of life itself” (see Rose 2007, Rose and Rabinow 2006, Rose and Novas 2005, Rabinow 1996). Groups congeal on the basis of biological identifications. They stake claims on the public purse on the basis of shared biological factors, such as genetic markers for disease. They also accept communal responsibilities arising from their own and others’ ‘vital’ needs. They cease smoking in public places, vaccinate their children, and fund public healthcare systems. In the domains influenced by biopower, populations develop “novel somatic ethics with obligations as well as hope” (Rose 2007, 8) and biological citizens “have an active stake in their health and that of others” (Rose and Novas, 2005, 36, my italics).

Transplant surgery might well have bred greedy individuals with cannibalistic instincts. However, it has also bred collectives dedicated to maximizing the biovalue of organs and tissues and redistributing it for the health and vitality of their enclaves. One
can argue about the proper place of organ transplantation in health resource allocation, but the network of somatic experts that enables organ transfer are striving to optimize the health of their societies, not their personal life expectancies. And organ donors – the central plank of transplant infrastructures – certainly can’t be said to be motivated by desperate attempts to live longer. This holds for deceased donors and their kin, but also for live donors who, at least in a North American context, gamble their own longevity to invest in the vitality of others. Viewed historically, the acceptance of organ donation in Europe and North America has been phenomenally rapid and widespread (Richardson, 1996). The transplant endeavour has been driven forward by the ascendancy of biopower in certain late 20th century collectives, not by a sudden surge in individuals hoping to evade death. It has involved new truth discourses about the vitality of organs, new strategies for intervening on collectives in the name of life (organ procurement agencies, organ donor cards, transplant teams, brain death legislation), and new modes of subjectification for the optimization of individual or collective health -- new ways of individuals working on themselves, to accept organs, but also to proffer them.  

One of the ways transplant recipients have worked on themselves to assume their role as ethical consumers in this economy of vitality is through the articulation of an ethos for their extended life and a distinctive eschatology for its eventual cessation. Death was never very far from recipients’ considerations. But their descriptions of spiritual connections and spiritual communities (both now and in the life to come) and their visions of the resurrected body were infused with a desire “to ensure, sustain and multiply life” (Foucault, 1976, 138). Traditional Christian theologies of life transcending
death were invoked, but the particulars were significantly reworked. The theological revisions reflected our growing capacity to administer ‘life itself’.

Fragile Life Extension

On a warm Sunday in spring I drove an hour and a half outside of Toronto to a smaller city to attend what was billed as a ‘Celebration of Life’. Hosted annually by the local chapter of the Kidney Foundation, the ceremony gathers together and commemorates the region’s live organ donors, kidney recipients and dialysis patients (many of whom are awaiting either a first or subsequent kidney transplant). Such ceremonies are increasingly common. They range in size from large, province wide services to smaller community or congregational events, to private rituals of remembrance and dedication.

This particular ceremony was a relaxed and communal affair. Attendees knew one another and event organizers personally. Ritual protocol was not rigidly enforced and, indeed, in recent years organizers have combined the celebration of organ donors and recipients with recognition of the foundation’s volunteers. Particularly striking was the contrast between the polished wooden plaques that volunteers received and the colour co-ordinated roses and carnations that each organ donor, recipient or dialysis patient received.

“Have you ever thought of doing plaques for the Celebration of Life side, or has that never really crossed your mind?” I asked the event co-ordinator, a sensitive and astute woman for whom this particular event rivalled Christmas as the apex of her year.
“Well,” she responded, “because of the variable nature of the illness to have a plaque on the wall saying ‘yea, your transplant!’ And then suddenly to lose it and have that plaque on the wall… I don’t know how that would be. It’s moveable, it’s removable, you know.”

A transplanted organ is fragile and transitory. Although there are exceptional cases of graft organs surviving 20 or even 30 years in their host, 15 years is considered a very admirable life span, and there are many, many transplanted organs that survive far shorter time periods. If life is extended by organ transplant, it is a very uncertain and precarious extension. What transplant recipients most often recount is a very acute sense of the provisional nature of this treatment, not a robust faith in the infinite expansion of mortality. As transplant recipients at the Celebration of Life came forward to receive their floral tribute, the event organizer encouraged everyone to say a few words “of any sort”. Invariably, recipients recounted how long they’d had their transplant. “10 years in August”, “18 and a half years”, “almost 11 years”, “not 2 years yet”. The accounts are not approximate. As telling as the fact that some five, ten or more years after their transplant recipients felt compelled to attend such a service, is their precise reckoning of exactly how long they have been granted their reprieve. An organ is a gift of life that teaches recipients to number their days.

Even beyond graft survival, recipients know themselves to be far from immortal as they struggle with the sometimes debilitating, sometimes life threatening, complications that frequently arise both from the immunosuppressant drugs that all transplant recipients must take and from the years of chronic illness and multiple treatments endured prior to transplant. For two seasons I paddled with Team Transplant,
a group of twenty organ recipients that compete in Dragonboat tournaments under the auspices of the Canadian Transplant Association. “Oh, it’s a lot of work to keep this boat filled,” sighed Sally, the long time team manager, herself a kidney recipient for thirty years and a dragonboat competitor at far more elite levels than Team Transplant. “People come and go according to how they’re feeling”.

I didn’t notice the additions or subtractions in my first year with the team – they were simply the good-spirited and congenial bunch that I paddled with. But in the second season I felt the team’s vulnerability. The team captain did not return; the immunosuppressant drugs that protect her liver transplant were adversely affecting her kidneys. Dale, a kidney/pancreas recipient in his mid-thirties and the soul of the team with his raucous cheerleading, was sidelined. Stress tests showed problems with his heart that his doctor insisted meant no physical exertion, not even cheering. Kendra paddled the second season with the cast that she must now permanently wear to protect the disintegrating bones of her foot, a remnant of the years of diabetes that preceded her pancreas transplant. Tina’s long-awaited knee replacement, necessitated by the effects of immunosuppressant drugs on her joints, had not yet transpired. She used canes to make her way to the dock, required assistance to get in the boat, and paddled in pain.

Transplant recipients know better than most that physical immortality is not to be had. They are certain that organ transplant has extended their life; they are equally certain that their lives have been shortened by illness and by medical treatments, including transplant. Several of the recipients in my study remarked that their life span would be far shorter than the average. As two-time kidney recipient Candice told me: “Life is fragile. It is anyway. But when you’re living with a transplant it’s even more
fragile.” Given the risks of the surgery itself, the precarious life of the transplanted organ and the propensity to serious health complications post-transplant (factors that the recipients I spoke with were acutely aware of) transplant is not predicated on a bid to live indefinitely. Is it a fear of death, unfamiliarity with death or an inability to resign oneself to death that propels recipients forward into the vagaries of organ transplant?

Historiography of death

An extensive literature argues that death in modernity is terrifying, isolating and denied. Death in most western societies has been transformed, in part by new medical knowledge and technologies, but more sweepingly by modern sanitation, clean water supplies, nutrition, and rising standards of living. Infant deaths are uncommon. Childhood diseases do not slaughter thousands. Women rarely die in childbirth. Men (and women) can realistically anticipate a productive working life ending in a decade or more of retirement. When in their later years people do succumb, it is more often in hospital or long-term care facility than at home (Walter, 1996). Aries (1974, 1981) argues that the circumvention of death in the populations of infants, children, young and middle aged adults, combined with the tendency to corral death to medicalized settings behind closed curtains where even the closest relative may not catch a glimpse of it and where public sensibilities will almost certainly not be impacted, equates to a “hidden death”. These trends make death in modernity both unnatural and taboo -- out of sight, out of mind and out of modern discourse. The exception, of course, is the litany of violent and catastrophic deaths that saturate the media; these “pornographic”
presentations of death, Gorer (1956) declared, were further proof of the impossibility of speaking of death as a natural and inevitable phenomenon.

When death does force itself on the scene it is, several influential scholars argue, acutely more terrifying than in previous eras. Death is inherently terrifying and knowledge of death continuously repressed, Freud argued (1939). Yet as the notion of the individual has gathered more and more weight in the philosophies and social structures of the West, our death, or the death of an individual important to us, is a far greater threat than in more communally oriented societies (Aries, 1981). Scholars also argue that death has become more frightening because the communal and religious resources that once tamed it no longer exist or have lost their power to shield us (Berger 1969). Increasingly, the confrontation with death is a lonely individual one fraught with unfamiliar terrors and existential angst.

This version, or theory, of modern death is not supported by the narratives of organ transplant recipients. Death for transplant recipients is neither hidden nor unfamiliar. It cannot be ignored; whatever terrors it holds must be directly confronted. Obviously, undergoing the highly invasive, painful and uncertain technology of transplant does not signal resignation to death. But neither is it an obdurate refusal of death. Transplant recipients are like wind surfers skimming over a lake of death. Certainly, the objective is to avoid falling in and they will use -- to the limit of their hope and endurance -- all the manifold attributes of wind and equipment to stay afloat. But the water is too powerful a force to be wholly conquered, too much a part of their horizon and too close to their skin to be denied.
Having interviewed twenty transplant recipients, twenty stories could be told of “looking death in the eye”, as Candice referred to it. This is inherently true of heart, lung and liver transplants where mortality is imminent for all recipients, and repeated crises and emergencies mark the route to transplant. But the close press of death is also felt in almost all narratives of kidney transplant (which is frequently distinguished in the medical and social science literature as a life-enhancing rather than a life-saving transplant). Aside from the threat of death carried by the failure of the original organ, transplantation is itself major surgery with all of the attendant risks. Moreover, it is performed on people who are invariably compromised from years of chronic illness, making the possibility of surgical death all the more plausible. Not returning from surgery was a tangible peril that almost all of my participants related facing. For several of my participants transplant did entail major complications and weeks or months spent in intensive care units with death as likely an outcome as life. Death is no longer typically personified (Aries, 1981). But if it were, transplant recipients would be familiar with its features.

This familiarity bred, many of them claimed, equanimity towards death. Candice described sitting at her father’s bedside as he passed away. “I’d never seen anyone die before, but you know what? If that’s what dying’s all about, it’s OK. Not that I’ve ever been afraid of death,” she added, a reference to her exposure since childhood to the presence of illness and the threat of death.

Heart recipient Domenic described the tranquility he felt in the moments prior to his transplant despite the roller coaster ride of emotion produced by the competing hazards of proceeding with the surgery and being disqualified from it. The phone call
from the hospital announcing an available heart had sent his own badly damaged heart into an irregular rhythm that made the pending transplant impossible. As he lay in hospital receiving medication to reduce the irregular heartbeat, a second heart became available.

They called my wife and what we call my transplant team. My wife’s sister and her partner jump in the car; drive over, pick up my wife and one of my daughters. So they come down to the hospital in the middle of the night.

They do a whole bunch of stuff to get you ready for this. Twelve vials of blood, shave, every test you can imagine. They poke holes in you, here, there and everywhere. They are all finished with me; my wife and family, you know, have been in. I’m in a little CCU room.

Now before I did it to myself, right? Whatever excitement, whatever keyed up… Well, I’m lying there, right? I’m feeling pretty, uh…


I’m O.K. I-am-O.K. Like if I’m makin’ it, I makin’ it and that’s great. If I’m not, well… But I’m O.K.

Not all recipients recount such detailed descriptions of the equanimity they found in the face of death, but their narratives frequently alluded to “not being scared”, “having made peace with death” or employed a sly black humour about their demise that belies theories of the taboo and terrifying modern death. Ironically, the one participant whose narrative sharply contrasted with this general trend -- stating that she had “huge terrors around death, huge, huge terrors” -- was a thirty year old woman who’d been born without functioning kidneys, received two unsuccessful transplants as a child and had for the last 18 years declined the option of kidney transplant, choosing instead almost two decades of hemodiaylsis. Fear of death does not propel people madly forward into transplant; nor is transplant a refuge from the fear of death.
If the modern death described by scholars as hidden and terror filled cannot be said to be the death encountered by transplant recipients, what sort of alternate understanding of death might characterize the transplant experience? And if the death denying, flesh preserving, rather dark immortality quests that dominate many social scientific discussions of organ transplant are not recognizable in the narratives of transplant recipients, what sort of immortality might recipients be striving for?

A number of scholars have acknowledged the incompleteness of our denial of death both in our psyches and our societies. “Our denial of death is indeed formidable, as Freud and the others have emphasized”, writes psychologist Robert Jay Lifton (1979). “But that denial can never be total; we are never fully ignorant of the fact that we die” (17). And while culture and society collaborate to help humans forget that they die it is paradoxically, Bauman (1992) instructs, language and association that affirms that we do.

Foucault (2003, 239-264) argues that the ascendancy of biopower in the 17th to 19th centuries re-conceptualized death in European societies, but this re-conceptualization was not a denial of death. Death ceased to be the fear of famine, the drama of a devastating epidemic, “the sovereign with his sword, executioners and tortures” (Foucault, 1976, 147), Instead, death became endemic. “Death was now something permanent, something that slips into life, perpetually gnaws at it, diminishes it and weakens it” (Foucault 2003, 244). Its permanence provided a constant target for the proliferating array of circuits, knowledges, and practices that functioned to administer life. “That death is so carefully evaded is linked less to a new anxiety which makes death unbearable for our societies, than to the fact that the procedures of power have not ceased to turn away from death” (Foucault 1976, 138).
Organ transplant is a turning away from death, even if it is not a denial of it. Its technologies, infrastructures, subjectifications and truths are part of the “administration of life,” the assault on mortality, that Foucault theorized as power’s sequel to the sovereign’s “right to death”. But transplant is a unique example of the administration of life, one that challenges aspects of Foucault’s history. Elaborating the relationship of death to this evolving power, Foucault (1976) wrote: “now it is over life, throughout its unfolding, that power establishes its dominion; death is power’s limit, the moment that escapes it; death becomes the most secret aspect of existence, the most ‘private’ (138, my italics).

What is unique about the technologies of transplant is that death is not power’s limit. The organs of deceased donors ensure, sustain and multiply life; death itself becomes part of power’s arsenal in the administration of life. Death itself is “mutable, improvable, eminently manipulable” (Rose & Novas, 2005, 5), as Lock’s (2002) examination of the fashioning of brain-death amply demonstrates. The fact that death is not power’s limit is, for many social commentators, the most disturbing feature of organ transplant technologies.

Foucault also claimed that in biopower’s dominion, death became secret and private. He described the diminishing pageantry of death, contrasting this waning tradition with the previous spectacle of a dying sovereign, the locus of power in an earlier symbolics (1976, 138). But the ritual and ceremony that surrounds the deceased organ donor (described more fully in Chapter 4) belies the assertion that death in an era of biopower must be secret, private and apolitical. Tony Walters (1994) concurs that there is little that is quiet or furtive about death in biopower’s current regime. “The
announcements that death is taboo and that our society denies death continue, yet death is more and more talked of” (1). Hospice care, bereavement counselling, do-it-yourself funerals, college courses on death and dying and other contemporary practises and discourses around death comprise, he argues, “a revival of death”. This revival of death, of which organ donation is surely a part, is perhaps a measure of biopower’s refusal to concede death as its limit. The administration of life now includes both the bodies of the dead and the processes of dying.

Suicide, Foucault (1976) argued, was the nineteenth century measure of how far the sovereign ‘right to death’ had receded. Suicide marked the right of the individual to determine their death. It proved “one of the first astonishments of a society in which political power had assigned itself the task of administering life” (139); subsequently it became the focus of much nineteenth century sociological analysis. Suicide, although still very much a ‘problem’ for sociologists and psychologists to solve, is no longer an “astonishment”. As death ceases to be a limit to biopower, the individual ‘right’ to die is being recast. As biopower extends its operations further and further into mortality, death becomes less a right, and more a personal responsibility. Pediatric intensivist Sam Shemie (2008), Bertram Loeb Chair in Organ and Tissue Donation, has remarked that today, more often than not, it is impossible for death to proceed without a medical decision being made. Resuscitation techniques, organ replacement therapies, respirators, pacemakers, intensivist and geriatric care – all exemplars of a power “situated and exercised at the level of life” (Foucault 1976, 137) – have made it possible in many cases for some semblance of life to continue until a decision is made to withdraw or withhold medical techniques. Ironically, biopower now requires many people to ‘opt out’ of life,
not in a dramatic suicidal flourish of rights, but in a more prosaic, managed exercise of the performance of individual responsibility and the governance of populations. Death, like life itself, often in the name of life itself, is administered.

Prior to such an end-of-life decision, biopower necessitates, for many, a commitment to “living with dying”. Arthur Frank (1995) argues convincingly that postmodern medicine has the ability to ‘manage’ (but not cure) large numbers of diseases that would previously have been fatal. The result is a significant number of people for whom illness is always in the background, and frequently in the foreground, of their experience. Frank dubs them “the remission society” and speaks of their “visa status” in the lands of health and illness. The standard illness narrative of restitution does not capture their experience and members of the remission society are forced to tell new stories, stories that grow out of a postmodern condition.

Postmodern medical treatments that do not remove the affliction but nevertheless prolong life by years or even decades result in a pattern of mortality that Tony Walter (1996) calls “living with dying” in contradistinction to the ‘hidden death’ that Aries describes. The experience of ‘living with dying’ and the social practices that contextualize that experience fundamentally change, both Bauman (1992) and Walter (1996) argue, our encounter with death and ultimately our understanding of mortality and immortality. In Walter’s estimate, traditional Christian views of life after death have been eclipsed by postmodern experiences, ideas and practises of death. For many, both Christian and secular, he claims there has been a turn to “heaven on earth”. Walter (1996) points to a continuum of health-related immortality strategies: striving for an immortal body through cryonics, various metaphysics of aging gracefully, and the more
widespread and “less dogmatic” philosophical imperative “to live as fully as possible” (158).

The trends Walter discusses are particularly relevant to transplant recipients, prototypical members of the remission society and adepts in the ways of ‘living with dying’. Organ transplant reconfigures bodies and assessments of the bodily resurrection. It fortifies promises of life everlasting in the fullness of life now. It transforms identities, relationships and communities, and frequently exhorts these transformations as eternal.

*The Ethos of Extended Life: to live as fully as possible*

‘Livers, kidneys, lungs and hearts!
We can’t live without these parts!
We’ve been given a second chance
To live, to love, to smile, to dance!
B—O---O---O---NE MARROW! And Pancreas!

The rallying cry of Team Transplant reflects an ethos that informed many of the recipients in this study. The resurrection transplant offers is the second chance to engage life’s relationships, opportunities and activities. It is a chance, not a guarantee, and it sustains not the possibility of living indefinitely, but the possibility (indeed almost the imperative) of living ‘more fully’. Having made it to a future they nearly missed, with no reliable projections of their transplant’s prospects, the present frequently took on epic proportions in recipient narratives. In Candice’s estimation it is the experience of illness that underscores the importance of the present moment and the successful transplant that allows her to live it fully.

All I’m certain of is right now. I don’t know what’s going to happen tomorrow. And that’s the way I’ve lived for, you know, as long as I can remember. But going through dialysis and the second transplant has really, really brought that home for me. This is it. This is it – for now. I know I’m alive now, I know I’m fine now. I don’t know if I’ll be fine tomorrow. I think
anybody who knows me would see that sort of living in the moment as a real attribute. Cause I’m not going to let anything get by me, that’s for sure!

The living, loving, smiling, dancing recipient at the heart of this ethos celebrates a ‘vital’ human being, not just in terms of biology, but in terms of affect: a person of unquenchable appetite and boundless zest. The ethos of living as fully as possible seems almost a necessary transposition of vitality from biology to character. For despite frequent forecasts, transhuman, posthuman or even ‘optimal’ futures have yet to fully materialize. Often Frank’s “visa status” more accurately captures the world of biopower’s subjects.10

Reflecting on a postmodern world of change and transience, Zygmunt Bauman (1992) argues persuasively that the immortality of today inheres in the current moment. “The time dimension of transcendence is turning here into a spatial issue: stretching the span of life is turned into the effort to stretch the capacity to live” (30). What Bauman describes as a general trend is intensified for transplant recipients. Chronic illness has a way of making the future so uncertain that it is not even imaginable, heightening the power and significance, the transcendence, of the present moment.

The present moment is the epicentre of living as fully as possible, but the ethos is not without theological implications. Lifton (1979) argues that at the heart of the experience of transcendence is a fundamental dialectic: “the human struggle to combine awareness of death, loss and terror with the capacity to feel, love, transcend and become whole” (34). In their desire for transplant’s ‘second chance’ and their acceptance of the uncertainty it carries, many of the recipients I interviewed strove to recognize and embrace both the fullness and the fragility of life; in doing so they saw themselves reaching for the transcendent.

**Spiritual Connections**

Transplant recipients complicate the conventional assessment that modern death is lonely. There are elements of the organ transplant experience that make the encounter with death profoundly isolating. Some recipients spoke of the overwhelming loneliness of their time in intensive care units where their severely suppressed immune systems meant
visitors were disallowed. Those who had received organs as children almost invariably commented on the bewilderment and sometimes panic they felt as treatments proceeded without their understanding or permission. The alienation recipients felt in a hierarchical and bureaucratic health system that discounted their embodied knowledge was endemic and almost everyone recounted strategies they employed (not always successfully) to obtain voice and agency. Several felt acutely the paucity of professional attention to the emotional and spiritual sides of organ transplant. The ability of the biomedical model to adequately respond to the emotional and social dimensions of personhood is particularly tested in the complex relationship between recipients and donors.

But within the recipient population there is evidence of a community that has formed around the shared experiences of that encounter. Most centrally, the receipt of an organ ensures that one’s experience with (hopefully averted) death is never entirely alone for it always involves the life and body of another. Although this connection can and does produce real tensions, many of my recipients strove to transpose this tension into an understanding of death – and life -- as communal, and not resolutely and irrevocably individual.

Some scholars have argued that the biomedical model champions the vitality of the body at the expense of the spirit and the supremacy of the individual at the expense of larger groups. It fails to see persons as holistic composites of body, mind and spirit as well as integral members of social networks (Gordon, 1988). It is this mechanistic view of the body and discrete view of the individual that undergird the rituals and protocols of the modern hospital (Davis Floyd, 1992). Scholars have commented on the ways
biomedicine has diminished personhood and fostered isolation and fear, especially in the treatment of the mortally ill (see especially Kubler-Ross, 1970).

But the transplant confrontation with death is not solely defined by isolation and alienation. However rigid the contours of the biomedical view of person, the concrete and cement of the hospital proved remarkably pliant as transplant recipients again and again transformed the medical domain into a site of companionship, even conviviality. Organ recipients do not face mortality bereft of community; even in the most astringent of settings their encounter with death frequently evoked emotional, spiritual and communal responses.

In some cases friends and family storm spaces designed to restrict them. There are varying tales of New Year’s celebrations with strings of lights around hospital windows and crowds of friends around hospital beds. In one narrative the merriment is provided by contraband champagne; in another it is the nurse’s welcomed vial of morphine. “It was one of the best New Year’s I’ve ever had”, says Kendra of the impromptu bedside party that took place days after her kidney transplant. “So, in all this, I’ve had some of the best moments of my life.”

In other cases friendships take root in the institutional corridors themselves, despite the sterility, the privacy curtains and the anonymity of hospital gowns. Sylvie described the very close bond that grew between herself and another liver transplant candidate in the liminal days of hospitalization as the race between their own mortality and the death of a suitable candidate took place. They shared X-ray results, estimations of doctors, Bible readings and religious reflections from their hospital beds. Their friendship endures in the years post-transplant.
Hemo-dialysis wards are particularly rich soil for such friendships. The wait for a cadaveric kidney transplant is longer than for any other organ, in part due to the number of people waiting for kidney transplants, in part due to the fact that dialysis means the wait *can* be extended. Like a part-time job that never allows holidays and never varies its duties, potential kidney recipients that dialyse in clinic literally spend years visiting the same ward, same patients and same medical staff three mornings (or afternoons or evenings) a week. Many travel to dialysis on the same assisted transit, hang in waiting rooms together, share snacks, trade jokes, mark occasions with cards and presents, take joint outings and even holidays (at dialysis retreats such as Camp Dorset). They get to know each other’s medical histories, even watch them unfold, and they get to know each other’s family histories as relatives visit the ward. Teresa and Walt met, courted and married while dialysing together. Walt would finish dialysing first and then come sit beside Teresa, sharing sandwiches and conversation as her blood pumped through the dialyser. She described their first kiss in the open space of the clinic under the gaze of the nurse’s station amidst the whirring and beeping of the machines.

We started a little…a little dialysis affair. I remember the first time he kissed me. It was on the unit. And we were just looking at each other: shall we do it? Cause it’s kind of an intimate place, like everybody -- you can’t sneeze but the staff all knows about it. So we deliberately made this lovely prolonged kiss and we figured, ‘that’ll have them talking’.

As Teresa instinctively knew, their kiss was not only romantic but also rebellious. It challenged conventions that see the chronically ill as asexual, contravened hierarchies that place the patient, childlike, in subordination to medical officials, asserted patient solidarity instead of patient segregation and claimed a transplant union that has been far too understudied in the literature on organ transplant – the link between fellow recipients.
The bond that has captivated scholars has been the tensile relationship between recipients and their donors, both living and deceased.\textsuperscript{12} But often, despite the tensions of this donor-recipient relationship, it is mined for evidence of human connections that are immortal. In live donation, particularly in the narratives of the first world where genetic and emotional relationships have largely been the prerequisites to donation, organ exchange is said to make an indelible, but equivocal, mark on the relationship.\textsuperscript{13} In the narratives of live donation told to me, the tensions of donation – the demands, expectations, silences, obligations – were indeed part of the way that transplant marked relationships. But live donation can also, despite very real propensities to divide, bear witness to a human connection enduring enough to intimate eternity. George and Candice, kidney donor and recipient respectively, were very frank about the stresses, the ambiguities and the costs of this corporeal exchange. “But there’s a connection,” Candice told me. “There’s a link between us. The word that he used is ‘inextricable’. And there is a certain quality of that ‘inextricableness’ there.”

Likewise, many recipients who receive an organ from a deceased donor insist that their donor is inextricably connected to them, conjoined with them in their struggle with death, and a companion in their post-transplant lives. But the (frequently sudden or violent) death of the donor and the transplant policy of strict donor anonymity insert ambiguity into this relationship. Sharp (2001) argues that procurement personnel regularly “dehumanize” donors through the professional and public erasure of the individual donor’s intimate personal identity. Recipients are likewise encouraged to adopt an objectified attitude to their newly acquired organ and sharply discouraged from personalizing their transplanted organs (Sharp 1995).
Although recipients are sometimes told the age or gender of their donor, the only sure knowledge they have about their benefactor is their sudden death and the generosity of a grieving family. From this poignant information and from additional detail drawn from the size of the organ, accidents in the vicinity at the time of their transplant, and ‘gut feelings’ recipients frequently spin elaborate identifications for their donors. Sharp (1995) delineates the fictive and often idealized characters that recipients typically bestow on their donors. Her account emphasizes the ways such constructed donor identities work to define a recipient’s new sense of self post-transplant. But more than personal identity is consolidated in recipient narratives of the deceased companion that braved death with them. In many narratives, and even more ubiquitously in the processed scripts of transplant events and donor memorials, the unseen companion signals the interconnectedness of all human beings and suggests the infinite continuity of persons and communities.

Her ‘mate’ and her ‘buddy’, as pancreas and kidney recipient Kendra calls her two donors, have become an intricate part of her spiritual and social life. They are a presence she feels – “when I’m alone in a room, I’m not alone type of thing. And when I do something and no one’s around to see it I feel like a proudness around me”. They are invoked in her nightly prayers. They escort her as two angel pins on the lapel of her coat. On the anniversary of her transplants she gathers friends to go for a drink to toast her donors. I was with her at one of these occasions, seated with about 20 others at tables pulled together in the middle of a busy downtown pub. ‘To Kendra’s transplant!’ someone called out and glasses were raised. ‘To my donors,’ she corrected quickly, raising her own.
The death of these two human beings and Kendra’s own perilous journey towards death intertwine to form a particular vision of this life, the next life and the links between them. “I call them angels because I don’t know what else to say”, Kendra elaborated.

I think it was even cultivated by me thinking that I might also die, and where will I be if I die? I pictured being an angel to other people. So me believing in angels also meant that maybe I can come back and… and be with you in that type of way. So it’s just, it’s a sense of community, it’s a sense of still belonging.

In these myriad ways – in the familial ‘transplant teams’ that accompany recipients to the hospital, in the gathering of friends at bedsides, in the blossoming of friendships and romances in clinical spaces, in the physical, emotional and spiritual bonds attested to between recipients and donors – the lonely, angst filled death that wanders the corridors of modern medical facilities is mitigated. Death, or the threat of death, is always a part of these relationships. “A really good friend of mine”, Teresa told me, “one day you’re at dialysis laughing with them and the next day they’re just missing.” Teresa also lost Walt. Not long after the wedding they were called, in close succession, for a kidney transplant. Teresa’s was a marked success, but Walt suffered rejection and the mega-doses of immuno-suppressants used to combat it were complicit in a downward spiral of health crises. Teresa buried Walt four years after their original dialysis kiss.

The links organ recipients make in the face of mortality are not a barrier to death, but a collective engagement with it. When I asked if there was anything spiritual or religious about transplant, Teresa responded after a long pause:

Knowing that I’m not an island. That there’s a community, a large community of people who themselves and their family are going through every bit as much hell as you are. And it’s a community you don’t want to belong to, but while you’re in it there’s, sort of…they’re very special family.
Like families, membership in the ‘remission society’ is by chance not choice.

Despite the enforced membership, Teresa’s perception is that this group’s shared ordeals afford links most effectively described as ‘blood ties’. The depth of those ordeals and the emphatic assertion that they are shared consecrates this ‘very special family’.

Connection forged and defended in the face of death’s ‘scandal’ contradicts it, intimates bonds more durable, more intractable than death itself. Lifton (1979) speaks of “the expanded and exquisitely connected soul or self” (32) created in transcendent moments where both death and infinity are recognized. It is this sense of connection that recipients carry beyond the hospital to a variety of transplant-related settings.

**Spiritual Communities**

Post-transplant, organ recipients are frequently active in a ‘transplant community’. Many participate in organ donation advocacy events and speak publicly to encourage donation. They take part in transplant sporting events such as Dragonboat competitions or Olympic-style Transplant Games. They volunteer as mentors to patients awaiting organ transplants. They write books, articles and letters about their transplant experience. They raise funds for health organizations that minister to people with organ failure. They revisit their dialysis wards or their transplant surgeons. They write anonymous letters to their donor kin. They attend donor memorial services. They enact rituals to mark their transplant.

This transplant community has two recognizable motifs: one is the joyful recognition of the resurrection of their lives and persons celebrated with images of
renewal and rebirth (Sharp, 2001). The other is an on-going awareness and
acknowledgement of ‘living with dying’. Those who have died and donated their organs
are recognized and memorialized at almost every transplant event. Those who are dying
or have died awaiting organ transplant are a ubiquitous presence. And far less publicly
displayed, but no less defining of the community, is the steady attrition of their own
members. I travelled north of Toronto, to Ontario’s cottage country, to interview two
sisters whose genetic disease had resulted in renal failure and who had both undergone
kidney transplants. Kate is a very well known figure in the Canadian transplant
community, a founding member of the Canadian Transplant Association, a regular
participant in transplant athletics and a tireless activist for organ donation. Her sister
Gillian does not share her enthusiasm. “I couldn’t stand it,” she told me, “to be always
making these friends only to watch them die.”

The opposing dispositions of the transplant community – the joy of renewal and
the sobriety of living with dying – are both integral to recipient practices, but rarely
conjoined, except in ritual. Perhaps this is to be expected for, as Bourdieu (1977) notes,
ritual is particularly contradictory precisely because it is a tool used to reunite the things
that practical logic has sundered (124). One particular rite of the transplant community
dramatically captured the conflation of these two communal themes.

At the large and colourful Toronto International Dragonboat Festival held
annually at Toronto’s Centre Island there is a special race featuring crews of women who
have had breast cancer (and often mastectomies) and who have taken up the sport of
dragonboating for several reasons, one of which is to build upper body strength. Team
Transplant also competes in this race. The men on the team are replaced with additional
women recipients, many who enter this one event only. The race unfolds like any other. The quick, terse cries of the start -- ‘Paddles UP!’ ‘Ready, Ready!’ -- and the crack of the gun set it in motion. The furious deep paddling at the beginning gives way to the longer, muscle-straining strokes that carry the boat down the 500m raceway. A drummer perched in the bow of each boat pounds out paddling rhythms and pursuit on a ceremonial drum. Coaches bellow their crews down the lane and call them up to a finish with passionate crescendo and ever-increasing tempo.

But after the boats have crossed the finish line, and the women’s out of breath cries of congratulation or commiseration have died away, they do not paddle away to the docks. Instead they jockey amongst themselves, circling and weaving until there are five boats in a straight line, alternately facing the spectators on each side of the river. Each woman reaches beneath her seat and raises high into the air a single carnation. ‘The women in these boats have travelled a long road to be here today,’ the voice on the P.A. system announces to the crowds. ‘The carnation they hold is in memory of the ones who were not able to make the journey.’ A hundred carnations stay aloft for a silent moment then arc gracefully through the air. Landing without a ripple, their gentle bobbing presence joins the festival’s celebration of brawn and vigour.

The official name of this race is the Health Awareness Cup. But in general parlance it is the Survivor Cup. And transplant recipients, no less than the women in the breast cancer boats, feel this ritual incarnates, in the forceful rush down the raceway and in the still surrender of their flowers across the finish, the thin line between those who escaped death and those who did not, and the continuing communion between them.
In important ways the recipient community that forms outside the hospital is an extension of the attempts within a clinical setting to embrace the dialectic of transcendence – the awareness of bounds of finitude and the assertion of connections that escape those bounds.

“When you do CTA events or Transplant Olympics or Dragonboat racing is there a spiritual overtone to some of that stuff?” I asked Candice.

Spiritual undertone, I think. And maybe it’s just in the bond that we all have. Maybe that’s part of the spiritual connection. It’s more than close, more than a connection. It feels like more than just ‘oh yeah, like we have something in common’. Like we read the same book or we saw that same movie. It’s more than that. Every single one of us on some level have looked death in the eye and have won. Not won – eluded it or whatever you want to call it. We’ve all been there. All of us to a certain extent or another. We’ve all been there.

Tony Walter (1994) offers a number of contemporary examples that suggest that the shared experience of loss generates a sense of community or revives it. He considers “the lengthened period of dying so common today” to be one of the fundamental reasons this form of community attains its current significance (198). In his estimation such communities have something vital to offer society at large, not the least of which is “a reminder to us all to ponder our priorities” (198). His claim, highly debatable, nevertheless points to the reverential quality that inheres in communities jointly founded on the administration of life and the awareness of mortality. Prayer, though not always formalized, seemed part of the sinews of this community. Many mentioned its importance, and several recipients noted that their sense of community was expanded by the knowledge that others were praying for them. Kendra made clear how that expansion included a cosmic element:

I had a lot of people praying for me. It made me feel, like whenever I’d go through this, people around me, people thinking about me, and that has to come from something bigger than mankind. That’s the way I look at it. So – could I define it? No. But do I feel it? Yup.
As if in response to these intimations of ethereal yet enduring community – community built on a shared biological identity, on shared experiences of loss (and rejuvenation), on commemoration and prayer, and on the embodied and imagined dimensions of the act of organ donation – recipients felt an overwhelming urge to “give back”. A very large percentage of the recipients I spoke with contributed their time and effort to transplant or other health-related causes, worked in the helping professions, or were active in religious or other service organizations. Sharp (1995) uncovered a similar pattern among the organ recipients she spoke with. Sharp considers this trend indicative of “ties that bind” in the exchange of organs (1995, 375). The urge to “give back”, she argues, stems from a desire to offer recompense for the organ they’ve been given, a desire rooted in what Fox & Swazey (1992) termed “the tyranny of the gift”. In publications through the 1970s, 80s and early 90s Fox and Swazey argued that organ transplant recipients felt guilt-ridden and discomforted by a gift whose exceptionality and magnitude they could not reciprocate. Such feelings, they argued, were heightened by the obligations of reciprocity that inhere in gift giving. Social scientific literature on transplant almost invariably invokes their argument.

“I do feel guilty,” pancreas/kidney recipient Dale told me, unprompted.

I waited with baited breath, expecting him to articulate haunting feelings of remorse about the donor’s sacrifice.

“I feel guilty every time I revisit my dialysis ward,” he continued. “How come I got lucky and not one of them?”

By circumscribing organ exchange to a circle of two, the ‘tyranny of the gift’ analysis hinders exploration of the larger social and cosmic fabrics that organ transplant
is woven into. Scholars are correct that the weave can be uncomfortably tight, but in a broader view the “fetters” (Fox & Swazey, 1992, 40) would include not only donors and their kin, but also other recipients, those who have not received transplants, those who received unsuccessful transplants and those with other life-threatening diseases. In short, recipient obligation extends to those in need of more life, as well as to the gift giver who has enabled the extension of their own life.

Recipients’ expansive sense of communal obligation expresses a subjectivity that owes more to the imperatives of biopower than it does to the “tyranny of the gift”. Recipients are the beneficiaries of a power that seeks “to ensure, sustain, and multiply life”. They are both its objects and its subjects, and they are, frequently, expositors of its “somatic ethics”: the hope for more life, the obligation to foster life (in individuals and collectives), and the re-visioning, in response to new biotechnologies, of who we owe that responsibility to (Rose, 2007). Many transplant recipients envision themselves as responsible members of a particular bio-society: the collective threatened or afflicted by organ failure\(^\text{15}\). They feel the compulsion to ‘give back’ what they received – not an organ per se, but the life it generated. They actualize this desire by “administering life” in their community, through patient mentoring, healthcare fundraising and organ donation advocacy.

The close circle of reciprocity implied in “the tyranny of the gift” does not convey the broad networks of connection and commitment recipients narrated to me. There was a sense that one cannot, and should not, measure the gift of life and mete it out in kind. In keeping with the dictates of a power that seeks “to invest life through and through” (Foucault 1976, 139), the gift of life should be compounded, promulgated, circulated.
This gift is meant to keep on giving, and recipients see their obligations to the economy of vitality as on-going. In this economy, the donors’ gift is not so much tyrannical as exemplary. In the hierarchy of conduct that orders the transplant community’s “somatic ethics”, organ donors are the pinnacle of right action. They enable recipients to live, and they epitomize an ethic of somatic responsibility for recipients to live up to.

To be sure, as Dale’s comment indicates, life is not distributed equitably; only some are “lucky.” The unlucky ones in this bio-society are the victims of organ failure who do not receive an organ in time and the victims of catastrophic trauma who become organ donors. Recognition of the disparities in transplant’s administration of life did produce feelings of guilt in some of the recipients I interviewed. Sometimes this guilt reflected concern for those waiting; sometimes it centred on the deceased donor. Kendra told me:

When I was in the hospital, I’m feeling blue, whatever. I did have the hospital chaplain visit. A lot of conversations I had with them were about continuing with my strength, but a lot of it was about my donor: “I’m feeling quite guilty about this, and I’m feeling whatever about this, and let’s pray for them together.” So there was a lot of like, ‘let’s keep them in the equation.’ And I don’t ever—not that I have a fear of it—want it to be something like take advantage of, or take them out of the equation, because it’s a huge something. You know? So I never want to be at the point where I never think of them, or I never think about their families.

Kendra dealt with her guilt about the unjust administration of life -- the inequity of an extension granted to her but not her donor -- with prayer and with a determination to cement the place of her donors in the bio-society she is part of: a society of donors and their kin, recipients (both waiting and realized), and somatic experts -- clinicians of various types, but also social workers, organ procurement agents, bereavement counsellors, dieticians, bioethicists, and representatives of the pharmaceutical industry. Somatic experts encompass all those “novel forms of authority” who, as Rose (2007) puts
it, “claimed to understand how we should live better lives” (27). Hospital chaplains are part of this array of expertise, although they are generally not remarked upon in discussions of “the experts of life itself” (see Rose 2007, 27-31). The role of religion and spirituality in the construction of bio-societies and in the play of biopolitics has not been fully explored. But traditionally religious discourse has authorized any number of truth claims and religious practice has strengthened any number of subjectivities. My respondents suggested that religion was an active force in the construction and governance of their somatic selves.

Recasting the tyranny of the gift in the theoretical framework of biopower and biopolitics also encourages reflection on the generative nature of power. The close weave of obligation, responsibility and morality that encircles recipients can be comforting as well as tyrannical, constitutive as well as binding. The organ recipients I spoke with insisted that their desire to give back stemmed from their sense that they were integral to this community. “The doctors will tell you the exact words that I say,” Domenic said, of his work mentoring patients awaiting heart transplants. “They say it – it’s like water running off the duck’s back. I go in and I sit down and I go through exactly the same kind of stuff, but I’ve been there. Then that’s so amazing, how it connects.”

Their desire to give back also stems from their sense that their journey – both physical and spiritual, both death conscious and life embracing -- has given them something inspirational, even revelatory, to offer people. They too are somatic experts. Their transplant experience affords them a novel authority on how to live better, i.e. more spiritual, lives. Finally, the desire to give back stems from a sense that they are bound,
not only by the tyrannical ties of transplant, but by enduring human bonds that emanate from somewhere beyond time and resonate in the present moment. What is new about this age-old intimation of spiritual connection and community is that it is forged, in this case, on a shared somatic status and our collective ability to administer life.

**Scattered Ashes, Scattered Organs**

“My body’s going to medical science when I die, I’m not being buried!” stated Dean, a tall, solid and outspoken man who when I interviewed him was awaiting a kidney transplant.

“All right?” I asked. “That fits with your faith?” Dean and his wife Corinne were evangelical Christians, very active in their congregation, an independent denomination.

“Okay, yeah,” he answered. “My personal faith. See, I don’t care what the church believes. I mean, I have to have my own…where I stand with God and what he tells me. He does tell me stuff. I mean, we’re his children. He’s my father, he talks to me. I don’t have a problem with it [donating his body to science].”

The recipients I interviewed were generally indifferent to the fate of the body in the next life. There are several possible reasons -- ranging from theology to ethics to experience -- that organ recipients, even those committed to Christian doctrine or communities, do not feel transplant poses a threat to hopes for continued existence in a life hereafter.

As Walter (1996) points out, contemporary beliefs about the afterlife are idiosyncratic and intuitive rather than doctrinally correct and the tendency is to emphasize an immortal soul, not a resurrected body. Scholars examining the
contemporary disposal of the dead have made similar points. Lawrence (1998) notes that in 1951 voluntary bequests of bodies for the purposes of medical dissection accounted for only 40% of the annual supply, the balance being culled from state-dependent, "unclaimed" bodies. However, willed donations accounted for 70-100% of the annual supply in the 1960s and 1970s. Lawrence notes Richardson’s argument that this rise in donated cadavers for dissection, and the attendant rise in cremation in the same decades, "stems from changing beliefs about life after death: a final decline of belief in literal resurrection and a broad social shift toward agnosticism and atheism" (137).

But Prothero’s (2001) book length account of the rise of cremation in North America makes decidedly clear that atheism and agnosticism were not, in any way, the impetus for the religiously charged renaissance of cremation rituals. What was instrumental in the eventual acceptance of modern cremation was a shift in certain religious beliefs and metaphors (from predominantly traditional Christian views to a more eclectic blending of religious alternatives) and "significant transformations in the theology of everyday life", including a divergence "from seeing the person as an amalgamation of body and soul to seeing the person as soul only" (12).

These theological shifts were accompanied by a changing morality, both within and without Christianity, concerning the ‘proper’ role of the body at death. Early cremationists, Prothero (2001) demonstrates, were part and parcel of the mid-19th century sanitation movement, where the drive to contain dirt, squalor and disease was simultaneously practical, aesthetic and evangelical. The emphasis on the beauty in utility continues in this century. It has new projects, but familiar antecedents. ‘Don’t Bury the Cure’, an omnipresent slogan in organ donation campaigns, was, many told me, a
particularly poignant plea. One with a particularly Christian inflection, some scholars might add. Lafleur (2002) draws a careful historical picture about the marriage of agape – selfless love of the other – and utility in Christian thinking and social practice in mid-20th century North America. He argues that these trends lent tremendous Christian support to the technology of organ transplant at the expense perhaps of more traditional doctrines about the body.

Finally, in his analysis of the ‘prior operability’ of kidney sellers in India, Cohen (2003) suggests another frame for considering the recipient disregard for the ultimate fate of the transplanted body. Cohen argues that India’s nationwide population “emergency” which saw women and men voluntarily undergoing tubal ligations and vasectomies at the behest of the state set the stage for Indian citizens, especially women, to consider their bodies open to the state and to the idea of selling a kidney. “The emergence of Chennai’s various ‘Kidneyvakkams’ must be located in the prior operability of these bodies” (2003, 667). Without diminishing any of the distinct concerns that the sale of third world organs generates, it is worth considering Cohen’s notion of ‘prior operability’ in relation to organ recipients of the first world.

For the vast majority of organ recipients, transplant surgery is preceded by prior operations – corrective surgery, preventative surgery, exploratory surgery, preparatory surgery; veins tied to arteries, blood added and removed, amputations and insertions and repairs. My interviews frequently included a site tour of scars and devices, patches and prostheses. “I overcame the ‘you’re not gonna cut me open’ stuff when I had a tour of the dialysis unit,” stated one participant. Recipients’ willingness to disrupt the boundaries of the body through transplant – as well as their willingness to discard
traditional concepts of the body resurrected whole and intact – is rooted in their prior operability.

As Bourdieu (1977) would have it, the body and its practises are central to the durable dispositions, the ‘habitus’ that envelops both. The relationship between how we do things – including medicine -- and how we think about things – including immortality –is reciprocal and self-perpetuating. Dean’s ‘personal faith’ about the resurrected body is based on the practise of his body in this life, a practise that includes a large amount of surgical intervention. His body has proved radically pliable and adaptable; it has not proved to be a dependable or consistent continuum even in this life. “Ideas of life and death must make sense of, or at least fit, the experiences people have and the settings they find themselves in,” writes Walter (1996, 4). The experiences of organ failure and organ replacement do not fit easily a doctrine of immortality that inheres in the constancy of the body.

*Commodified organs*

However, the lack of attachment to their own – and others – deceased remains is a source of concern for many transplant commentators. Some Christian ethicists worry that it signals a disregard for the Christian emphasis on an embodied soul, the importance of the body to being fully human (Meilaender, 1996). And a significant number of social scientists similarly claim that the harvesting of organs ‘commodifies’ the body – by this they generally mean the wilful divorce of person from the body, the devaluation of the body into a ‘thing’ like all other things, the willingness to market or exchange our most innate human attributes.
The notion of ‘commodity’ is traceable to Karl Marx who argued that a commodity was a distinct sort of entity: a product produced solely for the intention of exchange. These were objects ‘outside’ their producers that satisfied human want of some kind, having therefore within them a use value for others. Commodities were forged in the conditions of capitalistic exchange; the quality of ‘commodity’ inhered in its exchange, its transfer to another. Drawing on his labour theory of value, Marx argued that commodities were invested with a fetishlike power for their true worth (their production worth) was masked by a capitalistic exchange system that alienated workers from the products of their own labour.

Equally important to the conceptualization of commodities has been anthropologist Marcel Mauss’ (1990 [1967]) work on gift exchange. Mauss stressed the obligatory nature of gifts, their role in establishing and maintaining social relations, and the gift’s contradistinction to commodity. According to Mauss, commodity exchange was object centred, relatively impersonal and asocial. Conversely, the spirit of gift exchange inheres in spontaneity, sociability and reciprocity. The obligations of reciprocity build relationship.

In 1986 Arjun Appadurai edited a very influential collection of articles (of which Igor Kopytoff’s is most frequently cited) that debated the ideas of both Mauss and Marx, and more recent cultural theorists such as Baudrillard and Bourdieu, and asserted that one of the most significant facts about commodities was their non-static nature. One could trace the movements of objects in and out of commodity status, much as one would trace the biographies of persons, wrote Kopytoff.
Working with these foundational theories, scholars have deployed the notion of commodification in multitudinous ways. But one consistent and primary area of concern has been ‘commodification of the body’: the exchange of human bodies, their attributes or their parts, the modality of that exchange (gift, commodity, barter, theft), the impetus to such exchanges, the injunctions to such exchanges, and the political particularities and powers of the parties exchanging. Commodification of the body is generally viewed as repugnant largely because of the penchant in the West to conceptually separate people from things. This separation is rooted in classical antiquity and Christianity but was, Kopytoff (1986) claimed, “culturally axiomatic in the West by the mid-twentieth century” (84).

Frequently this division between persons and things is defended by invoking the moral philosophy of Immanuel Kant, which stressed that persons were ‘an end in themselves’ and should never be considered merely a means to some other end. Wilkinson (2001) notes that commodification of the body can reference both actual social practices of exchange and more metaphorical, attitudinal considerations. To view or speak of a human being as if they were a thing with exchange potential, i.e. as a means to some other end, is another connotation of commodification frequently employed in scholarly discussions. Bodies metaphorically commodified allow scholars to range over issues as diverse as the objectification of women in advertising or women ‘enslaved’ to the cosmetic surgeon’s knife (Sharp, 2000).

According to some, the “atomization” of the body (Sharp, 2000) is a primary threat to the conceptual separation of persons and things. ‘Persons’ are reinforced when they are considered in their totality, when the body is integral both in and of itself and in
its relation to ‘person’. The person is in danger of being denigrated to the status of thing or commodity when the body is fragmented, either literally or metaphorically (such that a woman is ‘reduced’ to a breast or to reproductive capabilities). In general, the two strands of commodification (literal and metaphorical) are said to reinforce or precondition each other.

In this divide between person and thing the corpse occupies a somewhat ambiguous position, but conventional religious and cultural practices have inscribed the coding of person onto deceased remains and have demanded their “respectful” treatment. Assessments of what constitutes respect vary according to culture, age and religious tradition, notes Lawrence (1998), but there is universal concern for appropriate respect for the dead. Lawrence also adds that denial of this respect for the dead has historically been used to inscribe class and power: “respectful decent burial was for respectful decent people” (1998, 115).

Human beings and their attributes have been and continue to be exchanged – in labour, slavery, prostitution, religious ritual and medical treatments both ancient and modern – but there is, Kopytoff notes, “perennial moral concern” over these activities. Such concern, he asserts, is addressed in part by legal injunctions, moral indictments, and strategies of singularization – an infusion of sentimental or sacred value that distinguishes this object from all others and limits or hedges its exchange (1986, 84).

The “perennial moral concern” that surrounds exchange of human beings and their attributes is enormously heightened and sharpened in discussion of the transplantation of organs. The exchange of organs from donors to recipients poses radical new threats to the division between persons and things. The technological ability
to find in the organs of the body use value for others, to lift the organ from its
concealment and cohesion in the body, to circulate and exchange what had heretofore
been stationary, integral and useful only to the person/body that housed it is undoubtedly
a new chapter in the biography of organs. As Sharp (1995) writes “this biography is set
in motion at the moment of donation when the medical history of the organ itself is
recorded…Thus, through the act of recording its history, the organ takes on, in essence, a
life of its own” (378).

Transplant threatens to commodify bodies both literally and metaphorically.
Commentators worry that the atomization inherent in the transplantation process
“objectifies” (Sharp, 2000) the human body and that this objectification can be traced in
the metaphorical assertions of organs as pieces of machinery, procurement rhetoric that
equates organs to agricultural crops waiting to be harvested (Sharp 1995, 369), and donor
memorials that ritually depersonalize and erase deceased donors (Sharp, 2001). The
objectification of organs and persons is said to be indicative of an attitude of
commodification that drives persons into the category of things and entices exchange
practices into the impersonal and asocial commodity realm.

The most clearly commodified organ exchange practices emerge in the third
world. Scholars have convincingly demonstrated that a third world organ market exists
and that the exchange of organs for money fortifies historical practices of commodifying
the bodies of the poor and socially marginal for the benefit or use of more advantaged
groups (Das, 2000; Scheper-Hughes, 2001, 2000; Cohen, 2003). Scheper-Hughes
comments that although the black market is centered in the third World, such
commodified exchanges “involve and implicate the USA and Western Europe. The
demand for organs in one area stimulates the market for brokers and organ sellers in other nations” (2001, 59).

Many social scientists feel the exchange of organs in North America will become increasingly commodified despite the current prohibition against the sale of organs and the legislated commitment to voluntary donation. They reference the exponential growth in transplantation possibilities, the refinement of chemical suppression of the immune system, and the extension of transplant to an ever-expanding pool of candidates. They describe how this creates an “artificial scarcity” (Scheper-Hughes, 2001) and note the resultant rise in the demand for organs, a demand that increasingly cannot be met by voluntary donation.

Pressure on the voluntary system is evidenced in the growing number of public appeals to alter either the gift relationship or the parties that might ‘gift’. Waldby and Mitchell (2006) describe the increasing interest in legalized markets to mediate organ exchange in North America (168-173). Even more seriously entertained by North American policy makers are attempts to introduce a model of “presumed consent” (currently enforced in some countries, notably Spain) whereby brain-dead candidates are presumed to desire the donation of their organs unless they have previously specified their objection.

Attempts to legislate presumed consent in North America have not yet been successful, but the gift relationship is currently being rewritten in more subtle ways. Some provinces now reimburse organ donors for expenses associated with the act of donation. Deceased donation is being extended from brain dead donors to donors who have died from cardiac arrest, an extension which requires the decision to donate and the
preliminary steps to ensure successful donation to be made in the moments before, not
after, death. Live donation (primarily of kidneys) is gradually being extended from the
previously limited pool of genetically or emotionally related donors to a potentially
unlimited supply of unrelated or anonymous donors. Scholars frequently assess this
extension as a form of commoditization given the attendant risk of market transactions
that might surreptitiously accompany such distanced exchanges. Changes to the living or
deceased donor pool require revisions to hospital protocols, not to formal legislation, and
are increasingly implemented.²⁰

Gifts

Against the creeping tide of commodification, North American transplant
professionals, legislators and supporters have erected one bulwark: the gift of organs.
The language, sentiment and ideology of the ‘gift’ pervades official, popular and
individual narratives about the exchange of organs. Organ transplant has engendered, as
Kopytoff said the exchange of human beings and their attributes invariably did, legal
injunctions, moral indictments and strategies of singularization. What fuses these diverse
responses to the transplantation of organs is their shared reliance on the dynamic of the
gift.

Policy makers in North America have prohibited the sale of organs opting instead
for a program of voluntary organ donation as willed by the donor and/or her kin. The
prevention of direct financial gain from the exchange of organs is felt to keep the
exchange firmly in the realm of the gift and even the names of federal legislation reflect
this guiding ethos (the Uniform Anatomical Gift Act in the United States and the Human
Policy makers exhort the sanctity of voluntary donation at almost every opportunity and numerous ethicists argue that exchange of organs as it is currently configured not only defends against the more commodified alternative, it inculcates the social and relational benefits that Mauss classically claimed for gift exchange. “The donation of organs” states ethicist and policy analyst Jeffrey Prottas (1994) is a community-building action of great emotional and symbolic potency. The gift is to a stranger; it binds the stranger to the givers in powerful ways... Though the recipients benefit directly and critically from their membership in this community, all members benefit indirectly... Altruism is valuable not merely for itself but also for the coherence it encourages. (1994, 172)

Christian spokespersons, as I discuss more fully in Chapter 1, have also made the voluntary donation of organs, the ‘gift’ of organs, the backbone of their defense against the immorality of posthumously disturbing the unity of the body/person. In the willing ‘gift’ of one’s organ(s) to another, donors are likened to luminous Christian figures – the Good Samaritan, angels, saints, even Jesus himself – and the act of donating or receiving an organ is said to embody (literally) key Christian tenets: sacrifice, stewardship, resurrection, faith. By enshrining the voluntary donation of organs in religious symbol, the moral injunction against the sale or barter of organs is implicitly, and frequently explicitly, underscored. “The decision to offer without reward a part of one’s own body for the health and well-being of another person” constitutes, according to Pope John Paul II (1995), “the nobility of the gesture, a gesture which is a genuine act of love”.

“Accordingly,” he continues, “any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally
unacceptable”. John Paul II’s statement makes clear both the religious significance of the gift of organs and the moral injunction against the erosion of that gift.

Amongst social scientists studying organ transplant there is considerable consensus that the rhetoric of ‘gift’ in procurement campaigns, public policy statements, media accounts of transplant, donor memorials and individual narratives masks the inherently or increasingly commodified exchange of organs and the accompanying threats to traditional understandings of personhood. “Policy makers work cooperatively and aggressively to perpetuate language that foregrounds gift exchange even as they consider the further commodification of the body through a host of marketing strategies”, states Sharp (2000, 315). Several scholars have argued that gift rhetoric contributes to the “fetishism” of the transplanted organ. The fetishized organ masks the true value of organs, the realities of production, and the person of the donor (Schepers-Hughes, 2001; Sharp 2000, 2001). 21

Disrupting the Gift / Commodity dichotomy

Outside the gambit of organ transplant, scholars have cautioned that Marx and Mauss may have drawn the distinction between commodity and gift too sharply and too statically (Appandurai, 1986; Bourdieu, 1977; Hoeyer, 2005) and with too much regard to Western discourses about the immorality of money (Parry & Bloch, 1989). In his review of anthropological studies of both traditional and contemporary gift economies, Frow concludes that “gift and commodity are not mutually exclusive modes of transaction since they tend to have in common certain forms of calculation, strategy and motivation” (as quoted in Waldby and Mitchell, 2006, 124).
These cautions inform Waldy and Mitchell’s (2006) attempt to critically reappraise the dichotomy of gift vs. commodity that “has organized bioethical and sociological evaluations of [human tissue transfer] for the last thirty years” (8). Waldby and Mitchell (2006) consider the “technicity” (182) that abounds in tissue transfer today – the fragmentation of donated tissues, the engineering of tissues, and the diversion of tissues’ journey from donor to recipient through laboratory processes, institutional complexes and global networks. They argue that what begins as a ‘gift’ of human tissue frequently acquires commercial value in today’s circuits of biotechnology and biocommerce. Conversely, they argue, biovalue can also foster social reciprocity and solidarity. Many biotechnical researchers in both the public and private sectors are “committed to maintaining an open-source biocommons, a public domain” (best exemplified by the Human Genome Project), and there are many instances of alliances built between biomedical research and non-profit patient alliances (185). On occasion biotechnology and biocommerce can, they suggest, promote the “gratuitous” circulation of knowledge and facilitate projects of public good as well as private profit.

Despite the significant differences between solid human organs and other types of human tissue, Waldby and Mitchell (2006) claim the dichotomous framework of gift and commodity equally untenable in the exchange of organs. Gifts of, and markets in, organs are hopelessly intertwined. The same values that promote discussions of legalized markets in organs (efficiency and equity) are the values that originally encouraged legislators to forbid organ sales (173). Black markets arguably developed in response to national legislation that insisted on voluntary donation (171). To illustrate the impossibility of assessing organs as either gifts or commodities they cite the case of a
family from Israel that worked through an organ broker to obtain a cadaveric kidney transplant from a U.S. clinic “willing to ignore waiting lists in favour of patients with ready money” (176). What appears a straightforward example of commodified exchange is complicated by the fact that the funds for this transplant were largely raised through voluntary donations, gifts bestowed by a sympathetic community in Israel (176).

Biotechnologies have made the rigorous divide between persons and things, like the sharp distinction between gifts and commodities, similarly hard to uphold. In keeping with Waldby and Mitchell, Rose (2007) emphasizes the ways biopower and biopolitics have “decomposed” vitality “into a series of distinct and discrete objects – that can be isolated, delimited, stored, accumulated, mobilized, and exchanged, accorded a discrete value, traded across time, space, species, contexts, enterprises—in the service of many distinct objectives” (7). While the atomization and capitalization of human vitality is unmistakeable, Rose notes that critics of the commodified body are not always clear about the grounds of their objection (39, ftnote 52, 269). “However,” he writes,

what is clear is that the classical distinction made in moral philosophy between that which is not human – ownable, tradeable, commodifiable – and that which is human – not legitimate material for such commodification – can no longer do the work that is required to resolve this issue: that distinction is itself what is at stake in the politics of the contemporary bioeconomy. (39)

The decomposition of vitality also complicates the relationship of the person to their body. Margaret Lock (2002) has convincingly demonstrated that deployments of brain-death in North America insist that the location of the person is in the brain, in the part rather than the whole of the body. In contradistinction to the situation in Japan, a brain-dead body in North America is alive, but no longer a person.
But transplant and other biotechnologies do not consistently suggest that the location of the person is in the brain, in the singular part. Biomedicine makes contradictory and ambiguous assertions about the location of the person. Nowhere is this more evident than in the emergent fields of genetic and immunological research where the coding of the human person in DNA makes each and every remnant of the body resplendent with the attributes of person (Lawrence 1998; Hoeyer 2005). While the designation of brain-death very much encodes persons into brains, dismissing the whole body as integral to person, transplant understandings are also haunted by the infusion of person throughout the body and all its parts. Were this not so, the phenomenon of rejection and the science of immunosuppression would not be the defining limit and central discourse of transplant professionals and organ recipients.

*Gifts of Organs; Codes of Conduct*

Given the ambiguities, complexities and contradictions inherent in organ transfer, dichotomous assessments of the Gift rhetoric – that it either protects against the forces of commodification or camouflages them with sacralized, fetishized language – seem equally unconvincing. As Pamela Klassen (2004) points out in the context of consumption and motherhood, “the very language of theories of consumption themselves [commodity, fetish]…put religion to rhetorical use without necessarily considering it in itself” (265). Scholars of religion have pointed out that the fetish, from the Latin *facere*, ‘to make or to do’, has long been the centre point of controversies over what counts as authentic making (Chidester, 2000, 227; Klassen, 2004, 265). David Chidester’s insights
about the dual nature of the religious fetish in popular North American culture, its suspect claims and its legitimate sacrality, are particularly helpful. He writes,

Although the fetishized object might inspire religious moods and motivations, it is constantly at risk of being unmasked as something made and therefore as an artificial focus for religious desire...the challenge [is] exploring and explicating the ways in which such ‘artificial’ religious constructions can generate genuine enthusiasms and produce real effects in the world (2000, 228).

I would suggest that the rhetoric of the Gift, with its sacralized language and Christian antecedents, is a religious construction, one often challenged as inauthentic but one which has nevertheless generated genuine enthusiasms and produced real effects in the world (see also the fuller discussion in Chapter 5).

One ‘real effect’ has been the establishment of organ donation as a form of political and moral conduct. In the series of lectures entitled *Security, Territory, Population*, Foucault (2007) designated the art of governing men, taking care of populations, disciplining conscience and directing conduct as “pastoral power”. Foucault claimed Christianity as the model and incubator for pastoral power, but suggested that the problematization and proliferation of conducts migrated beyond ecclesiastical borders. “So there was not a transition from the religious pastorate to other forms of conduct, conduction, or directing. In fact there was an intensification, increase and general proliferation of this question of these techniques of conduct” (2007, 231). The typology, organization and mode of function that typifies pastoral power, wrote Foucault, “is doubtless something from which we have still not freed ourselves” (2007, 148).

The rhetoric of the gift of organs is a form of pastoral power designed to act on individual and collective conduct. The state is not the origin or point of reference for
this power, and its objective (the conducting of conduct through the techniques of
guidance, salvation, submission and truth) must certainly be seen as broader than the
reduction of organ scarcities (the objective implied by the ‘fetish’ critique). The
practice of organ donation, as framed by the rhetoric of the gift, is a conduct with
social, ontological, eschatological and ritual implications.

Whether or not the ‘gift of life’ sustains social networks or generates social
solidarity is debatable. What seems less arguable is that the rhetoric of the gift (and
the various other ways ‘gifting’ is ‘conducted’—professional procurement personnel,
required request legislation, donor registries and donor cards) make this end-of-life
practice something of a social obligation. One may consent or decline, but it is
increasingly difficult not to consider the request. The ‘gift rhetoric’ works to ensure
that everyone knows the expected code of conduct. However, this code of conduct is
not merely obligatory. Many donor kin claim to find solace in their sacrificial act.
Live donation now includes individuals who donate their kidney to an unspecified
stranger rather than someone they know. The gift rhetoric elevates organ donation; it
is a conduct that is laudatory, noble and generous, as well as expected.

Recipients also feel the social obligations inculcated by the rhetoric of the gift.
Their conduct is equally targeted. “If I ever did anything to jeopardize my [donated]
liver, it would be like spitting on the grave of the person who gave me this gift”, one
transplant athlete told me. Transplant athletics is itself a form of conduct that derives
from an appreciation for the generosity of the gift. Maintaining their health, their
energy and their desire to “live life to the fullest” are related conducts that likewise
stem from an awareness of the gift, and the gift giver.
Perhaps precisely because the administration of life in this instance is so thoroughly intertwined with the bodies of the dead, eschatological visions and spirit voices are notable accompaniments of the conducts shaped by the designate of the “gift” of organs. Reflecting on her kidney and pancreas transplants and the slow return of her eyesight after diabetic complications resulted in the removal of one eye and temporary loss of vision in the other, 32 year old Kendra remarked:

You know, it’s not very likely to have a life altering experience, and I think I’ve had three: the two transplants and getting my eyesight back. And ‘three’ has since become very significant because of those events. Two donors, one recipient; a lot of threes type of thing. And when I’m having trouble kicking myself out of bed in the morning, it’s like ‘Kendra, you can kick yourself out of bed’, and you do it. So it’s almost like answering to three – sort of, but not necessarily spirits -- it’s being led by three individuals, rather than just by myself.

“If felt like a gift”, Kendra told me at one point, struggling to explain the ways her donors have entered into her constructions of self, her cosmological understandings and her daily conduct.

*Death in the administration of life*

Transplant scholars acknowledge the ambiguity of the transplant exchange, despite their pointed critiques about transplant’s commodification of the body. “Organ transactions today are a blend of altruism and commerce; of science, magic and sorcery; of voluntarism and coercion; of gifting, barter and theft”, writes Schep-P-Hughes (2001, 43). What is significant about this quote is the absence of religion or spirituality from the list, indeed, the substitution of magic and sorcery in their stead. This chapter has attempted to seek out the spiritual dimensions of recipients’ encounter with death in a particular 21st century terrain shaped by the practices and discourses of biopower.
Most centrally, it has argued that death remains visible and vital to the lived experience of organ transplant, the cultural constructions of this life-administering technology, and the spiritual meanings and encounters inherent in both. The averted death of organ recipients inculcates a desire to find out why they’re here and a practice of ‘giving back’ both what they’ve found (spiritual insights) and what they’ve received (more life). An awareness of the fragility of life informs a recipient ethos of living as fully as possible. Loss, as well as rejuvenation, is embedded in their biosocial communities and inculcates the spiritual bonds said to solidify such communities. The spirits of dead donors fortify these communities and the conduct becoming to them. They also fortify recipient intimations of possible immortalties.

This chapter has also explored transplant’s ability to generate life from the bodies of the dead and the attendant concerns this has raised about the commodification of the body. Following Waldby and Mitchell (2006), I have questioned the dichotomous classifications of ‘gift’ and ‘commodity’. I have argued that the rhetoric of the gift can be profitably explored as a technique of pastoral power, shaping the conduct of actual recipients and donors, but more broadly, “conducting death” – our rituals of death, our understandings of death, our eschatological hopes and our posthumous responsibilities.

Organ donation is in some ways a revolutionary conduct. The bodily resurrection, and the various conducts it endorsed and established, has been for centuries a guiding ontological construction in Western societies. At least in part, the resurrected body has been displaced by the proliferation of techniques and practices aimed at administering life in individual and collective bodies. Biomedicine and biotechnology have recalibrated
ideas of life and death, eroded the constancy of the body, and cast suspicion on the various constructs and conducts that grew out of that constancy.

A “counter-conduct,” Foucault (2007, 194) explained, was a revision of previous conducts and objectives, a suggestion of “how to be guided better, more certainly saved, maintain obedience better, and approach truth better” (231) – and yet still be both conducted and conductible. The rhetoric of the gift of organs inculcates a ‘counter-conduct’ – in deeply affective language and sentiment it ‘counters’ the truth and salvation traditionally revealed in the bodily resurrection (a promise of the continuity of both persons and bodies after death through the recollection and reassembly of all their parts) to present its own vision of deeper truths and better conducts. The deeper truths and better conducts that inhere in the rhetoric of the gift of organs? Not the individual seeking of life everlasting through the death of the saviour of all, but rather the commitment to ensuring, sustaining and multiplying the life of all through the death of the individual. Not the transcendent immortality of salvation, but the immanent immortality of sacrifice. Not the collection of parts, but rather their dispersion. ‘Don’t call this my deathbed,’ begins a long poem continuously recycled in transplant related publications:

Let it be called the Bed of Life, and let my body be taken from it to help others lead fuller lives.

Give my sight to the man who has never seen a sunrise, a baby’s face, or love in the eyes of a woman.
Give my heart to a person whose own heart has caused nothing but endless days of pain.

Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchildren play.
Give my kidneys to one who depends on a machine to exist.
Take my bones, every muscle, every fibre and nerve of my body and find a way to make a crippled child walk.

Explore every corner of my brain. Take my cells, if necessary, and let them grow so that, someday, a speechless boy will shout at the crack of a bat and a deaf girl will hear the sound of rain against her window.

Burn what is left of me and scatter the ashes to the winds to help the flowers grow
If you must bury something, let it be my faults, my weaknesses, and all prejudices against my fellow man.

If, by chance, you wish to remember me, do it with a kind deed or word to someone who needs you.
If you do all I have asked, I will live forever. (Test, 1976)

1 The succession of lives that the Buddhist or Hindu soul encounters is precisely for the purpose of spiritual refinement in preparation for nirvana, the deathless realm. Even the Taoist litany of techniques designed to assist humans in becoming immortal – alchemy, asceticism, hygiene and dietary rules, yoga, magic and petitionary prayers – are simultaneously practices to attain accord with the Tao, the unchanging Unity and First Principle that underlies the phenomenal world. And while it is technically true that going to hell makes one immortal, in the religious traditions of the West this is hardly the eternal life that is sought. Without a moral correlate, immortality is God’s greatest curse.

2 In significant ways my study cannot be considered representative. The recruitment process for this project was not designed to ensure a random sample of transplant recipients. Potential participants were told that the study was interested in questions of religion and several participants came forward precisely because they wished to talk about the religious dimensions they perceived in their experience. Secondly, through the snowball effect of participants recommending other participants, half of the recipients interviewed are involved with the Canadian Transplant Association, a transplant advocacy group. The impetus to join such an organization often stems from the conviction that the transplant experience is rich in spiritual implications. While this study cannot, therefore, conclude that the receipt of an organ is a spiritual experience for all or even most it does highlight the necessity of probing the religious dimensions they perceived in their experience. To explore what (some) people say is spiritual about transplant is a valid undertaking – if only to know how it contrasts with other transplant populations, other religious phenomenon, and other interpretations of the technology.

3 To be dealing almost exclusively with participants of Christian heritage is also not representative of the organ recipient population. While the study size is too small to draw conclusive findings, one tentative suggestion may be that the Christian metaphors and allusions -- the gift of life, body as sacrifice and as redemption, care for the stranger -- used in the public and professional sphere to rationalize transplant and encourage donation (see Lafleur 2002, Hogle 1999, Lock 2002) may predispose those of Christian heritage
to view the transplant experience in religious or spiritual terms – hence the disproportionate number of participants of Christian background who self-selected to participate in a study on religion and organ transplant. The reticence of ethnic populations to embrace organ donation, and in some cases receipt of an organ, may reflect not only their religious and cultural misgivings about the procedure (see Lock 2002, Sanders 1995, Bowman 2004) but also the failure of the Christian inflected transplant rhetoric to inspire those of different faith persuasions.

4 Rabinow and Rose (2003) argue “the ways in which we understand and relate to ourselves as human beings is under transformation.” They see a shift from the 19th and early 20th century “understanding of ourselves as creatures inhabited by a deep interior” to contemporary practices of biopower that construe the self as more biological than ontological (xxxi). The power and the promise of the body is central to these seekers because their search takes place amidst the “molecular games of truth” and techniques of biological optimization that render our bodies as ourselves -- “central to our expectations, hopes, our individual and collective identities” (Rose, 2007, 105).


6 At its heart, biopolitics is concerned with administering the vitality of populations. Foucault (2003, 239-264) delineated birth and mortality rates as the first objects of knowledge for this fledgling power. Forecasts, statistical estimates and overall measures were the mechanisms introduced by biopolitics. Their purpose was “not to modify a given individual insofar as he is an individual, but, essentially, to intervene at the level of their generality” (246). But the collectivizing moment that Rose, Rabinow and others allude to is not only the regulation of populations, but the tendency for groups to form around the basis of biological identifications.

7 This helpful tripartite definition of the elements of biopower – truth discourses, strategies for intervention on collectives and modes of subjectification – is drawn from Rose & Rabinow, 2006.

8 Kidney failure, if untreated, is fatal. Renal failure may be the primary disease or it may be a side effect of another disease that threatens health and life in additional ways. Dialysis technologies used to treat end-stage renal failure are not complication free, carrying the risk of blood clots, heart failure and life threatening infection. The treatment tempers but does not eradicate the effect of renal failure on the body: blood pressure control is erratic, dietary restrictions are stringent, anaemia is endemic, excess fluid weighs on the heart and lungs, toxin levels remain well above optimal. Over time the effectiveness of the dialysis may diminish; in a few cases the treatment may even become impossible due to repeated infections in peritoneal patients or lack of viable access sites in hemodialysis patients. The patient’s overall health is generally in steady decline.

9 Rose and Rabinow (2006) also comment on the increasing ‘responsibilization’ inherent in the expansion of biopower.

10 Waldby and Mitchell (2006) argue that the fantasies of regenerative medicine have been “nurtured inside transplant medicine” (179) and that the cultural desire for life-extending technologies fuelled by other tissue economies (cell lines, embryos, etc.) increases a “sense of entitlement” (162) to clinical therapies such as organ transplant, ultimately validating and expanding organ black markets. My sense is that the vagaries of organ transplant are hard to reconcile with the fantasies of regenerative medicine for a large number of potential recipients. The number of recipients receiving illegal organs is notoriously difficult to ascertain, however, it remains a very small percentage of the overall recipient population.

11 This discussion is limited to the recipient experience. Certainly the brain-death of cadaveric organ donors is frighteningly isolating and technical. It is graphically described by Hogle (1997) and Lock (2002).


13 This is not true in the published narratives of organ exchange from live donors in the third world (Das 2000; Schepfer-Hughes 2000, 2001; Cohen 2003) where poverty, limited public health care, and markets for organs reshape the narratives of donation.

14 I can understand Gillian’s reserve. Two of my twenty respondents, and three other recipients whose acquaintance I’d made in the field, passed away during the course of this research.
Bio-society is Rose’s term for communities “organized around the commonality of a shared somatic or genetic status” (2007, 134). A significant number of recipients identify with this bio-society and feel the compulsion of the somatic ethic. Certainly not all do. As Rose (2007) notes, the overlapping forces that produce the responsible and self-identifying “biological citizen” also produce “new types of problematic persons – those who refuse to identify themselves with this responsible community of biological citizens” (147). My recruitment methods ensured that I interviewed many more ‘responsible biological citizens’ than I did ‘problematic persons’. For one of the few counter-narratives I collected, see Leroy’s story in Chapter 3.

Nor is it clear that all segments of the general populace, to whom organ donation appeals are directed, have relinquished their concern for a bodily resurrection (Sanders 1995).


In Ontario, the Program for Reimbursing Expenses of Living Organ Donors was introduced in 2008. Toronto General Hospital is said to have conducted the first unrelated living kidney donation in Canada, proceeding with a donation recruited over the internet (www://uhn.ca/media/releases/2006/feb/organ_donors.pdf). In British Columbia a research project entitled Living Anonymous Donation has proceeded with the first in a series of 10 unrelated kidney donations (www.transplant.bc.ca/LADS_main.htm).

Lock (2002) follows Marx’s line of argument about fetishes, but briefly concedes that fetishism of organs might also reference their “magical or religious power”. “Contradictions are rife”, she states (320).
Chapter 3:  
Something with a capital S: Virtue and Wonder in the Experience of Organ Transplant

Hume, Freud, Weber, Berger and others, notes Thomas Tweed (2006), “are right in suggesting that religions interpret and ease suffering: disease, disaster, and death.” Yet, Tweed writes, following another strand of theorizing in religious studies, “religions [also] provide ways for humans to imagine and enhance the joys associated with the encounter with the environment and the transitions in the lifespan. Humans want something to say and do in the face of wonder” (72).

Likewise for my participants, the confrontation with death and the inklings of immortality were central to, but not exhaustive of, their religion or spirituality. This chapter explores the ‘wondrous’ in the accounts of these organ transplant recipients -- visions, presences, unusual emotional states, dramatic conversions, prayers answered with prescient timing or astonishing results. Such episodes were intimately tied to their illness, their transplant or its aftermath and invariably recounted as wondrous, in some sense of the word.

I do not agree with Lesley Sharp (2006) that the strange coincidences and convergences reported by both transplant recipients and donor families are best classified as “ghost stories” (147) told to help “make sense” of the tragedy of the deceased donor and the disrupted identity of the recipient. More helpful is William James’ (1902) insight that communication with the divine—or the dead—has psychic validity. “Unseen realities” elicit human reactions as immediate and as strong as those elicited through the five “material” senses (53); such accounts are not reducible to narrative conventions. In The Varieties of Religious Experience, James argued convincingly that religious
experiences have pragmatic force: shaping and directing human action, forging knowledge (of God, the universe and the self) and fostering moral development. In other words, religious experiences chart the future as much as they make sense of the past.

Many of the specific claims James makes (about the nature of divinity, the characteristics of religious experience, and the virtuous self such experiences give rise to) are heavily inflected by his era and his religious convictions and cannot be seamlessly melded with the narratives of 21st century organ transplant recipients. Nevertheless, James’ definition of religion -- “the feelings, acts, and experiences of individual men [and women] in their solitude, so far as they apprehend themselves to stand in relation to whatever they may consider the divine” (1902, 31) -- is the starting place for the discussion of religion in this chapter. And James’ conviction that the fruits of religious experience are seen in the metamorphosis of the self informs my understanding of the wondrous in the lives of organ transplant recipients.

Maxine

AM: so your sister was driving you to get your blood checked at the hospital?

Yes. So we were sitting in the parking lot. And she didn’t start to open up the door to come around and help. She sat there and she turned to me and she said: “I want to talk to you about something very serious.”

And I said “O.K.” I didn’t catch on.

And she said, “I’m getting my blood tested today too.”

And with that declaration I knew. You just know! And I didn’t say anything like “why? Is there something wrong with you? You too?” I looked at her and I was speechless. I don’t think I was surprised as much as I just thought this is a very, very important, pivotal moment. This has got to be handled the way I want to always remember it – as I handled it and she was able to handle it, the best way that was the best for us.
And I looked at her and I said, the first words out of my mouth were, “Thank you.” Cause I had to think about it for a few minutes. And then I looked at her and I said: “You want to be my donor.”

She said, “Yes, I very much want to be your donor.”

I first saw Maxine on the front seat of a school bus, her slight figure and her shiny brown hair bouncing into view as she laughed and talked with her seatmates across the aisle. I was attending the Canadian Transplant Games in Sherbrooke, Quebec and the bus was taking a large group of organ recipients from the sporting events at the university campus to the annual donor memorial service held at the large cathedral in town. “That’s Maxine Creary,” said the woman beside me as a vivacious peal of laughter wafted back to the middle of the bus, “you really need to talk to her.”

That wasn’t the first time I’d been told I really needed to talk to Maxine. Not only at the Games, but also in Toronto, when I spoke about my interest in the spiritual component of transplant Maxine’s name was frequently mentioned. Given the fact that Maxine has always lived in Newfoundland, her nation wide glow was intriguing enough for me to seek her out. I introduced myself and we arranged to talk by phone when she returned home.

And talk we did. One night’s phone conversation turned into two, punctuated with interruptions and return calls as each night one hour stretched to two and then to three. There was a sense that she had much to tell me. Certainly in the recounting of a life full of illness and medical crises -- the diabetic convulsions of her childhood, the threats to her vision throughout adolescence, the kidney failure of early adulthood, the pivotal moment of her kidney transplant in the very early days of transplant to diabetic recipients, a decade of diabetes complications that saw the amputation, successively, of
all of her toes and finally her right leg below the knee, and the more recent ordeals in her early fifties of hip replacement and a fall that had broken her collarbone and dislocated her shoulder. But there was also much to tell me about a life of “reaching out” as she put it – to family, to friends, to fellow transplant recipients (“I like to meet as many people as I can on each team from each country”, she said of her many trips to the Transplant Games) – and a life of figuring out: her body, her society and her faith.

Raised in a Roman Catholic family (but one, Maxine stressed, more interested in the spirit than the letter of Catholicism), educated in the Catholic school system, even attending Catholic boarding school in Halifax for a year, an 18 year old Maxine found herself “totally surprised”:

that my faith in God, my belief in God (cause I was taught who God was as I was growing up) was waning. It was getting weaker and weaker. Until I got to a point where I couldn’t call myself a Christian anymore, if I was going to be honest with myself.

What she has since become, Maxine maintains, is spiritual. She spoke of a kind of communication -- a connection -- that operates in the spirit, for those who are open to it. She describes this openness as both transcendent, “a gift,” and immanent, an individual “discovering journey”. Conversation, quiet thought, reading, and a healthy dose of soulful TV and radio programming are her spiritual stimuli. “I didn’t join this and join that and try to—I didn’t search for it,” she told me. “I searched within myself for it, more so. And I listened also.” Searching and connecting, reflecting and communicating have cemented her initial intimations: “I believe,” she stated firmly, “in Something. Something with a capital S.”

The pivotal moment of her sister’s donation of a kidney became an inaugural moment in her spiritual life. “I’m more spiritual now than I was then,” Maxine
comments, “but I think [the transplant] was a lot about awakening or re-awakening my spirituality, whereas religious I hadn’t been for years.” Indeed, Maxine described to me, in a blend of rich image and bald fact reminiscent of many a Newfoundland storyteller, one particular transplant moment that awoke and then ceaselessly sustained her conviction of spiritual realities.

Maybe two days before the actual surgery we were both in the hospital, so naturally I was allowed to visit her…. And the night before the surgery I told her that I had made up my mind that I didn’t think (I thought it would be too dramatic for both of us)--I said to her, “let’s say goodnight on the phone.”

And when we said goodnight, I wished her a good sleep and she wished me a good sleep. And we said to ourselves -- and this was really the spiritual part -- we said “you know what, it’s not in our hands anymore. We have made the decision.” And I think she said to me, “it’s in God’s hands and it’s in the hands of the doctors now.” And I agreed. I said “absolutely”. We both knew that we (either one of us, or both if by some really, really strange happening) could die.

And I slept well that night. And she said she did too. And I woke up during the night and, unbeknownst to the nurses and doctors, I went to her room. I knew where she was. And I walked in and I was very, very quiet. And I stood there for half an hour at least and I looked at her.

And many, many thoughts, as you can imagine, went through my mind. And I was very calm. And I said, “I will not wake her up to be awake one more minute than she has to on this day on which she’s being very, very courageous.” She needs all the courage she can get. I don’t want her awake longer than she has to be. In case she is much more scared than I think she is, much more scared than I think she’s showing me.

And I cried. And I was being very careful not to wake her. I wouldn’t sniff. I had forgotten to bring tissue; just using my hand. And I said, “Look, Maxine. You’ve got a dressing gown on, this dressing gown can be washed.” And I was thinking these thoughts, I was being so practical and I was being so… I was being so spiritual and I was being so filled with love, absolutely filled with love.

You know -- if you called me anything else but a human being the next best word would’ve been: “Oh, what is that ‘thing’ standing there? Only a body?” “Oh, that’s love. We call that love.” Cause I was so filled with it. I wasn’t Maxine. I wasn’t even a woman. First, I was probably love. And hope. Love and hope. And if that’s not spiritual, I don’t know what else is.
Kate

“Don’t give up. Don’t lose that sense of humour. And ASK QUESTIONS!!”

This is the advice that Kate Green extends to patients with organ failure waiting for transplants. Staccato delivery, accent on the imperative, the drummer Kate marches to plays in double-time.

“My doctor says to me: ‘Kate, no moss grows under your feet.’ I mean, Vern calls me the energizer bunny: I just keep going and going and going.”

“It’s also a pain in the butt,” her amiable husband Vern protests good-naturedly from the other room.

“You love the pain in the butt,” she rejoins.

From the snap of her blue eyes to her short, crisp hair Kate exudes the resolute grit of a fighter who’s been knocked to the mat and come up swinging. She narrates each epic setback and each uncertain recovery with the same stubborn preface: “I was bound and determined...”. Now fifty years old, there have been many.

I was 18 and I saw the specialist at Wellesley. He says, “I want to do a biopsy. I think the deafness is Alport’s.” I was in hospital for a month. And then he told me, “You have Alport’s Syndrome. It occurs more in men than women, and you might need a kidney transplant by the time you’re 45.” Course I had 3 by the time I was 31.

In the span of those three transplants and the myriad medical procedures that surrounded them – frustrating years of hemodialysis in her northern Ontario home, three hours from the nearest clinic with her 19 year old sister attending her; removal of her failed kidneys, her parathyroid and her spleen; fractured bones and other transplant related complications – Kate learned the importance of not giving up, not losing your sense of humour and, especially, of asking questions. For one question she failed to ask
led to a gross medical error that nearly cost her life. It also occasioned a religious
encounter that twenty years later continues to inform and perplex her.

Anyway, I went down to the clinic [in Toronto]. And I was so freaked out because they
said my [first transplanted] kidney was rejecting, I wasn’t paying attention to what they
wanted to do. All I could hear them say was they wanted to do some procedure. And I
said O.K.

Well, it turns out now (hindsight’s 20/20): he was putting a subclavian in to dialyse me. I
have a perfectly good fistula!!
[A fistula is the previously established access in her arm for hemodialysis needles, used in the months prior to the transplant.]

Anyway, when he was putting it in he punctured my lung. And I went “ahhhhh!” And
he said, “Oh, I think I punctured your lung.” And I went “oh”. So I remember sitting
there on the gurney and he went and got the portable x-ray machine. Took an x-ray,
came back and said it was a little pinhole. It would clear up. And he sent me home. On
the bus [to northern Ontario].

So three days later I was coughing up blood. And the worst part was…it was my
cousin’s wedding and I was in her bridal party. I was bound and determined I was going
down that aisle.

But anyway I’m sitting on the couch one night, coughing and coughing. And it was dark.
And I wasn’t paying attention. And I finally opened my eyes up and I’m covered in
blood. And I can barely breathe. I can barely walk. But I got my friend to the
hairdresser’s and after to the mother-in-law’s where we’re all getting dressed. And
Gillian [her sister] took one look at me…..

So, off to the hospital in Toronto….

Anyway, I don’t remember a lot of it. Don’t remember the next six weeks. I know they
dialysed me right away and they took 8 kilos of fluid off me.

That night they put me in ICU. And they called Gillian and other family members to say
I’m not going to make it through the night. I had a tracheotomy to make me breathe. I
had tubes coming out my toes, my arms. Gillian said it was so awful because the worst
part was the ICU was not even a room, just all curtains, and they were wheeling dead
people out. And then I’m in there. Three times they called: I’m not going to make it.

The ICU they put me in, there was a clock by my bed. And every once in awhile I’d
wake up and see the time. And with the tracheotomy you can’t talk anyhow. But I just
remember one night I woke up and there was a bright light by the end of the bed. And I
got up—
The only way I can describe it, it was a man--and the hair...and he had a white suit on (that’s the only way I can describe it) with big lapels. And the hands. The hands were doing this. [Beckoning.] And I remember clinging to those bed sheets. Shaking my head back and forward. I’m not going, I’m not going, I’m not going. It was just a really neat feeling, kind of floating. And I was: I’m not going, I’m not going, I’m not going.

Anyway, I just passed out or whatever. The next day the doctor said to Gillian, “she’s going to make it.”

When I finally came around and the doctor pulled the trach out, my first words were “what the hell happened?” He said, “Kate, you were so sick.” He said, “We had done everything in our power. In the end it was between you and the big guy upstairs.”

Kate has always been a member of the Anglican Church; a child in the Sunday School with her three sisters, twenty years a volunteer organizer in the century old church of her northern hometown. She plays organ for the services, prays for members of the congregation, yet often described God, not as her protector, but as her antagonist.

Discussing death’s inevitability, she informed Vern: “I’m going to go out of here kicking and screaming -- and I hope you’re listening God!” When the second transplant failed Gillian insisted, tear-stricken, that God had plans for her yet. “Well I wish he’d fill me in” Kate responded. To the doctor who performed her third transplant, she announced, “The big guy keeps knocking me down and I just keep picking myself back up. What else can I do?” Her perception of an adversarial deity is no doubt rooted (at least in part) in the fateful tussle of wills she experienced that night in the ICU.

Nevertheless, it is that same event that feeds her faith. “Yeah,” she told me, “I believe in God. I mean I have to after what I saw—whatever I saw.” Kate remains uncertain about the identity and the intention of her visitor, reviewing it in her own mind and discussing it with others many years after the fact. When a friend countered her customary interpretation of God calling her to leave life -- “He might have been saying ‘get up and walk’” – that, she told me, “reversed the whole thing!” And to the new
minister at her church she recently confessed, “I don’t know who I saw.” The minister suggested it might have been Jesus, in spite of the incongruous image. “Maybe they were his hands,” Kate allowed. “I don’t know. But something was making me raise off that bed.” The nature of the deity who visited her remains open to interpretation; the fact of the visitation does not.

Alina

All this up until now: very bumpy, suffering, disappointment. Being labelled—was going downhill, yet not being able to treat me well, but labelling me for being a troublemaker. This hypochondriac individual who has medical knowledge and uses it, you know, for her advantage. That was what I was going through.

Now I’ve come to the point where I had this (my fever shoots up again to 40 degrees centigrade) severe abdominal pain, so I go back…. And the doctor on call she came and she said, “Alina, we have to really go in and see what’s going on”…. They gave me the contrast [for the CT scan]. So sick I cannot drink it, so sick….

This was where my spiritual calling came, was when I started becoming spiritual.

Do you have time, or am I taking too much time?

AM: No, no. I have all the--it’s your time I’m taking so no, please.

So you have time?

AM: I have lots of time, yeah, no time limits.

So this is a very, very spiritual, enriching experience for me. So I’m going downhill, downhill, downhill and I’m reaching the bottom. I’m waiting for this CT to be done, trying to drink the contrast, but in the meantime I’m holding a cross. It was brought to me from Jerusalem, from near where Jesus’ tomb was supposed to be. And I had it often, I wear it often, but I never prayed on it.

This day, I know that I’m hitting the bottom. I’m hitting where I’m going to face death. I’m not getting better. And I’m holding this and I’m saying, “Jesus Christ” – and I’m praying with my whole heart – “if you are present just give me a sign. I need to know if you are there.”
High heels complementing her small stature, glinting gold jewellery accentuating both her stylish appearance and the drama of her story, Alina told me of her genetic polycystic kidney disease, the horrendous complications of the peritoneal dialysis used to treat it, and her eventual transplant, in richly accented English. Raised in the Armenian diaspora of Africa, Alina and her mother now reside in a modern, upscale condominium in Toronto. Alina’s father died, as did most members of his family, at age 50 from the same disease; neither transplant nor dialysis were available to that generation. Alina went into renal failure at the age of 48. She is now in her fifties, living (as she put it) “on borrowed time”.

The family’s Armenian heritage inflects Alina’s speech, her religion (she belongs to the Orthodox Armenian Church), and her cooking (I was solicitously invited to stay to dinner and sample their cuisine). A psychiatrist by training and profession, Alina works at a Toronto hospital; a fellow Armenian doctor was instrumental in helping her establish her career in this country.

Alina’s narrative was a tangled weave of emotion, religion, medical detail and psychiatric observations; equally complex was the combination of intracystic haemorrhaging, infection from the peritoneal dialysis and misdiagnosed uterine fibroids that led to her dire condition in the emergency room awaiting her cat scan.

For nearly twenty minutes I was praying. In the meantime I had drank this water and then suddenly, you know, I vomit. So I ask my mom to go out and get someone to clean it. But surely she cannot see; she cannot see clearly. She goes out and calls this guy. And this is an orderly; she just meets an orderly by chance, not a nurse, not somebody else. And this orderly comes in. And in the meantime I’m sitting on my chair, just praying wholeheartedly.

And so this is my miracle, which I tell everybody because this is the miracle I had. I was sitting there and the guy comes and instead of cleaning, he closes the door. He comes and puts his hand on my shoulder. And he says, “I’m going to pray now. Whatever I
say, repeat after me.” So he prays and everything. And I don’t know any English prayers. I didn’t even understand the word, what “righteousness” meant. It was the first time I’d heard it. And he prayed. And I prayed and I prayed and I prayed.

In the meantime, he was looking at the door, you know. You do something like this, they catch you—you’re in hot water. I know how costly…

He didn’t know me, I didn’t know him: nothing. He didn’t even ask my name. He just prayed on me. “Oh my goodness!” I said to the guy when he finished. And then at the end he said, “Release everything to Jesus, give yourself to Jesus, leave everything into his hands and he will guide you.”

And then I look at the man. “Oh, my goodness, but I was just praying, you know, for a sign.”

After this encounter, Alina’s illness narrative had a different trajectory. The CT reveals the uterine fibroids so long misdiagnosed and mistreated. Numerous medical hurdles still loom before transplant is even a possibility (including a hysterectomy so complicated by abscesses, infection and the size of the fibroid that doctors warn it may necessitate a colostomy and “a bag for the rest of my life”). But, Alina related, “from this time on, everything was working for me; I am protected.” Hospital staff so often experienced as obstructionist and contemptuous, apt to regard her as “histrionic” and “difficult”, become suddenly tractable:

I go to my hospital. I bypass the emergency. Doctors one after another lined up. They come, they see me, the surgeon comes, the disease guy comes….nurses are super with their treatment.

Surgeries, even the most problematic, proceed smoothly. “I had all these things done; everything I did was one step higher. I had no complications, no complications.”

She is finally stable enough to receive a kidney and is called in short order.

They told my mom that it was a good, a very good kidney. I didn’t need to have any further dialysis. It connected right away with me, and since then I have never had any complications.
But it was done before I had my transplant, long before my transplant. You know, the way God—this is the way of the spiritual….

If my mom was not there, I would say I was hallucinating.

_The fruits of religious experiences_

Religious experience, James [1902/1963] claims, is the purview of the “sick soul.” Such a soul intimates a world where evil is inherent, melancholy intrinsic, despair endemic. There are things that can neither be fixed nor controlled. The impress of such a world moulds a posture of surrender and elicits a desperate cry: “Help! Help!” The prolific religious experiences of the revival camps, James argues, reflected the dynamic of the sick soul: “you must first be nailed on the cross of natural despair and agony, and then in the twinkling of an eye be miraculously released” (228). Without resorting to the dichotomy of the sick and healthy soul (a device James uses to make several arguments), it is possible to locate the pattern James describes in the accounts above. Desperation and concession -- be it the despair of cure, the urgency of ICU, or the relinquishing of agency and expectation (“and this was really the spiritual part; we said ‘you know what, it’s not in our hands anymore’”) – precede the inexplicable encounter and the sensations of release, rejuvenation and salvation.

James’ morphology of religious experience does more than describe: both the psychic validity and the moral validity of religious experience intentionally come to the fore. “It is natural,” James writes,

that those who personally have traversed such an experience should carry away a feeling of its being a miracle rather than a natural process. Voices are often heard, lights seen, or visions witnessed; automatic motor phenomena occur; and it always seems, after the surrender of the personal will, as if an extraneous higher power had flooded in and taken possession. Moreover the sense of renovation, safety, cleanness, rightness, can be so
marvellous and jubilant as well to warrant one’s belief in a radically new substantial nature (228).

For James, the fruits of religious experience are constituted in this “radically new substantial nature”. “Conversion” most accurately describes the movement of the self and James describes in detail the emotions and cognitions that accompany it: the ecstasy of happiness, the loss of worry, the perception of new truths and a new world (248-252). Such emotions and cognitions signal the new character that emerges from the conversion experience, the “saintly” character who sees life as wider than the world’s selfish little interests, radiates inner security and equanimity, reins in conflicting and petty aspects of the persona to discharge them, unified, in ideal pursuits.

Conversion was also attested to in the accounts of my participants. The religious encounter was frequently tripartite: a rejuvenation of their physical person, a spiritual awakening, and the dawning of a new “self”. Always a churchgoer, Alina explained the spiritual relationship that has grown in the wake of her “miracle”:

We go to church, we pray, but it was more mechanical. You know, inducing yourself, psyche yourself up to pray. It didn’t have the same meaning as it does now. That understanding that God lives in us, and a little bit of spiritual being is in us, and that spirit is working to connect with us. I’m more aware. There’s a sense of awareness that just comes over you.

“Spiritual strength” (which she described alternately as “a positive energy” or “an inner peace”) was also a product of the religious encounter. This peacefulness altered her personality and generated a commitment to those alterations:

If you have a form of positive energy living in you, you are able to trust very psychologically disturbed patients. And I feel that energy. I don’t know, maybe it’s not the right word. But it is a quality I feel and that they feel -- they say, ‘You’re very kind…’. They’re picking up on something. I feel I’m more attuned to their suffering. Oh, there are days that I don’t, you know, there are too many other issues in my head. They can distract you away from that and then you become very impatient. But overall, I try to do that. That’s a big change.
“Whatever was given to me,” Alina related, “helped me grow better, spiritually and physically.” In this context, to “grow better” would seem at once a statement of cure and an assertion of character.

If Alina’s conviction of newfound virtue (and newfound protection) falls somewhat short of the lofty attributes of “saintliness,” this disqualifies neither her testimony of religious encounter nor her sense of metamorphosis. The elevation of character pursuant to the religious encounter is, James notes, relative: “there are higher and lower limits of possibility set to each personal life” (239). Nevertheless, he admonishes, “a small man’s salvation will always be a great salvation and the greatest of all facts for him” (239).

What unites both the saint and his “small” compatriot is the superseding of conventional morality (the “athletic attitude” of the “stalwart” dedicated to “personal will and effort”) by the non-volitional emergence of character, the organic flowering of virtues, the recognition, grounded in the surrender and salvation of religious experience, of “well-doing as the hollowest substitute for that well-being” (47).

I want to tie these two core Jamesian insights – the religious encounter as harbinger of the virtuous character, and the competing moral variants of well-doing and well-being – to the wondrous accounts of my participants and to a broader discourse about virtue in contemporary moral philosophy (and bioethics). There has been a paucity of attention to the moral dimension of the “ghost stories” of transplant recipients. Similarly, moral philosophers have understudied the portent of religious experience in the formation of the virtuous character, an extension “of the unfortunate fact that James is neglected by contemporary academic philosophers, with a few honourable exceptions” (Taylor, 2002, 22).
Cramps in our moral thinking

Moral philosophy, “particularly but not only in the English speaking world” has been truncated, Charles Taylor [1989] argues, by its focus on “what it is right to do rather than what it is good to be, on defining the content of obligation rather than the nature of the good life” (3). Richard Rorty (1997) shares Taylor’s frustration with this Kantian view of ethics and identifies several additional “non-Kantian” contemporary philosophers: Annette Baier, Alisdair MacIntyre, Michael Walzer (140). Although each thinker has different philosophical and political agendas, what they might be said to share is the rejection of the idea that morality can be produced by reason and rationality, articulated in universal laws, and executed in the individual choices and obligations of (reasonable) selves. Their explication of alternative understandings of morality is frequently cast as “retrieval” (Taylor, 1989; MacIntyre, 1981), but it is a retrieval that conjures up new visions of moral selves and moral communities.

What is crucial to grasp in their articulation of morality is its intimate association with emotion, passion, intuition, sentiment and feeling. Utilitarian calculations of various maxims, theoretical formulations of universal ‘oughts’, resolute projections of the will have little to no place in their moral constructions. ‘Reason’ no longer orchestrates the moral realm, but is reworked to signal both something less and something more than the machinations of logic. “As long as the wrong, external model of practical reason holds sway,” Taylor (1989) writes, “the very notion of giving a reason smacks of offering some external considerations, not anchored in our moral intuitions, which can somehow show that certain moral practices and allegiances are correct” (75). Conversely, Taylor advocates for practical reasoning as “reasoning in transitions”, the aim “to establish, not
that some position is correct absolutely, but rather that some position is superior to some other” (73). Support for our moral intuitions can be found in practical reasoning that progresses by description of “the higher mode of life and feeling” (rather than by argument on points of action) (75). “If we cease to think of reason as a source of authority, and think of it simply as the process of reaching agreement by persuasion,” concurs Rorty (1997), “then the standard Platonic and Kantian dichotomy between reason and feeling begins to fade away” (146).

When reason is excised from its hallowed place in moral schematics, with it goes the onus on rational, choosing, finite selves bound up in what it is right to do, and in its place arises the evolving self, creating what it is good to be, in the ceaseless interchange of authoritative social traditions and individual practice. It is this interchange, argues MacIntyre (1981), which inculcates the virtues: those qualities that foster the goods internal to practices, define the goods of individual lives and sustain the traditions “which provide both practices and individual lives with their necessary historical context” (207). Virtues change, MacIntyre demonstrates, with the evolution of new social structures, new cultural practices and the new narratives of plot and character they give birth to. Similarly, Taylor (1989) stresses the contingent moral self and its realization in practice: “We come to understand in part what really characterizes the moral states we seek through the very effort of trying, and at first failing, to achieve them” (48).

Lifting morality from the domain of the rational, choosing, individuated self, situating it in a “good life” rather than “good action” ties morality ever closer and ever more inextricably to moral communities. Emphasis on a moral community in which the structures of moral systems and the lives of moral actors are tangled and embedded is a
dominant feature of non-Kantian ethics, however described. “Moral community is a
related by tradition, history, experience, ideology, language, culture (one or more of the
above), but a group related, too, by values and ways of doing things.” Perhaps more
evocatively, Taylor (1993) elaborates “the inescapable framework”, the ideas and
pictures particular to social groups that underlie our sense of respect for others, our
notions of a full life and our sense of dignity (14). Michael Walzer (1994) is particularly
helpful in describing the ‘thick’ morality of communities and its divergence from (and
primacy over) ‘thin’ morality. Our “cramped” notions of morality have led us to believe
that men and women everywhere begin with some common idea or principle or set of
ideas and principles which they then work up in many different ways. They start thin, as
it were, and thicken with age, as if in accordance with our deepest intuition about what it
means to develop or mature. But our intuition is wrong here. Morality is thick from the
beginning, culturally integrated, fully resonant, and it reveals itself thinly only on special
occasions, when moral language is turned to specific purposes (4).

Inexorably tied to praxis and emotion, to interdependent and pre-existing
communities, ‘what it is good to be’, ‘the nature of the good life’, emerge as questions
that admit of no final, universal or static answer—for nations, groups or individuals.
Contingent, divided, plural. These are the maxims of contemporary moral philosophers
intent on departing from a Kantian worldview; they describe both moral selves and moral
communities.

All selves are self-divided (internally differentiated) in three different ways…First, the
self divides itself among its interests and its roles…Second, the self divides itself among
its identities; it answers to many names…Third, the self also divides itself among its
ideals, principles, and values; it speaks with more than one moral voice—and that is why
it is capable of self-criticism and prone to doubt, anguish, and uncertainty. Walzer, 1994,
85.
Likewise, “the moral communities we traverse are many. They overlap. They sometimes conflict with one another” (Lawry, 1993). Moral dilemmas are not so much opposing arguments, Rorty (1997) writes, as they are divided loyalties, divides between alternative selves, alternative self-descriptions, alternative ways of giving a meaning to one’s life. “One’s moral identity is determined by the group or groups to which one cannot be disloyal and still like oneself” (141).

To build any ‘sense’ or cohesion from the disparate fragments of selves and the competing allegiances of groups, a tremendous reliance is placed on narrative. It is a “basic condition of making sense of ourselves,” writes Taylor (1989), “that we grasp our lives in a narrative” (47). Such a statement echoes MacIntyre’s (1981) discussion of lives (of selves, communities and traditions) unified by narratives. And MacIntyre’s discussions are expanded in Ricoeur’s (1992) complex arguments about the nature of identity as both “sameness” (idem) and “selfhood” (ipse) – the latter refracted in “the struggle to faithfully interpret one’s life by a subject that is continually refiguring itself through the stories it appropriates as its own.”

Ricoeur’s postulate of the continuous nature of the narrative task is a staple of contemporary non-Kantian philosophers, and many would find accord in Ricoeur’s (1992) delineation of the triad of narrative identity – “describe, narrate, prescribe” – to suggest how “the anticipation of ethical considerations are implied in the very structure of the act of narrating” (114).

“The turn against theory and toward narrative” is arguably what unites and edifies collectives as well as individuals. Human solidarity, writes Rorty (1989), “is to be achieved not by inquiry but by imagination, the imaginative ability to see strange people as fellow sufferers…That is why the novel, the movie, and the TV program have
gradually but steadily, replaced the sermon and the treatise as the principal vehicles of moral change and progress” (xvi).

The “cramps” which “philosophies of obligatory action…put in our moral thinking” (Taylor, 1989, 103) have received careful working out in the alternative moral philosophies of a number of contemporary theorists. The hallmarks of their moral re-thinking include attention to emotion and intuition and a turn to narrative. Following both pragmatic and post-modern strands in philosophy, plurality and fragments are privileged over unified selves acting out universal maxims. The reclamation of virtue theory is often a focus. One of the fruits of their labour has been some tentative second thoughts in the field of bioethics.

After Duty: expanded moral thinking in bioethics, organ transplant and the religious encounters of recipients

In the fields of bioethics and medical sociology, Paul Ramsey’s (1970) treatise, The patient as person (in particular his detailed discussion of organ transplant and donation) stands as an instructive, foundational, and deeply moral text. In describing the “covenant” that ought to govern physicians and their patients -- unwavering faithfulness to the irrevocable dignity of the person -- Ramsey sought to build an ethical floor that both physician and patient might stand on when faced with the dizzying array of problematic decisions posed by contemporary medical technologies.

Given Ramsey’s stature in these fields, there is a revolutionary tinge to William May’s (2002) charge that Ramsey’s moral foundation was not moral enough.

An ethical floor provides a firm resistance to any and all rationalizations on behalf of medical progress and ingenious interventions that might distract physicians from their exceptionless responsibilities to their patients as persons. Yet the image of a floor
inadequately describes the full range of the moral life; it requires a building above it. (May, 2002, xl)

The building, May elaborates, would attend to the ordeals patients and families face, ordeals that “do not wholly admit of solution” (xxxiv). It would emerge in the aftermath of the fraught medical decision, in the attempts of patients to “rise to the occasion” of their illness, their treatment, their losses—and their gains. Illness generates displaced persons, May argues, and necessitates the reconstruction of identity, a project more adequately captured by an aesthetic metaphor than a legal one. The floor is essential, May concurs. But medical ethics also needs to attend to the “full moral world of patients” (xxxiii) and their need for “not simply a dwelling place that shelters them from the elements, but an ethos, a range of customs, practices, and ways of being that protect and support not only human survival but flourishing” (xl).

May wishes to deliver more than a critique of Paul Ramsey’s shortcomings; he wants to identify what “cramps” not only Ramsey’s moral thinking, but also bioethics as a field. His conclusion echoes the arguments of the philosophers explored above: “Ramsey’s work, like most ethics to follow in the next two decades, dealt with disease and death within the parameters of a principle-oriented theory of ethics” (May, 2002/1970, xxxiii). May’s “non-Kantian” affinities are a minority view in the field. Arthur Kleinman (1999) notes “the principle-based methodology still in command today”, “the persistence of a rather narrow Anglo-American analytic philosophy as the discipline’s canon,” although he perceives a “ ‘new bioethics’, more inclusive of alternative approaches” gingerly making its way into the embrace of the field (69).

Their positioning at the edges allows ethicists with non-Kantian philosophical persuasions to make some prescient observations about the moral imperatives that (often
implicitly) dominate bioethics. Frank (1997, 132) argues that the field has been structured around two principle-oriented foci. The first is the patient-clinician relationship and its incessant articulation in codes of rights and responsibilities that ensnare all patients and caregivers (but work, Frank asserts, primarily to resolve issues caregivers grapple with). This foregrounding of the moral desires of the medical institution, the clinician and the ethicist is termed “medicocentricism” (see also Kleinman, 1999). The second focal point is a telescopic and relentless attention to the ethical dilemma, “the moment of decision,” “quandaries of the sort that precipitate the involvement of a hospital ethicist” (Frank, 1997, 136) in order to administer “universally applicable principles and adjudicatory rules to health care conflicts” (Charon in Frank, 1997, 132).

In bioethical treatments of organ transplant these principle-oriented foci are ubiquitous—from the discourse of donor rights and recipient responsibilities to the endless dispute of ethical conflicts: the moment of death, the moment of (required) request, best practice in the allocation of organs, organ scarcity and organ markets. Many of these conflicts are precisely what shape Ramsey’s (1970) ethical inquiry into transplant and his principled resolution of a covenant of care and the exceptionless rule of patient dignity. Yet, if one were to move past the “ethical floor” that is currently both the ground and horizon of ethical treatments of transplant—what would a less medicocentric, more aesthetic, morally wide world of patients look like? And how would it be constructed? In their broader discussion of bioethics at large, the correctives Kleinman (1999) and Frank (1997) assert are suggestive.
First, as in contemporary non-Kantian moral philosophy, the turn is away from theory and toward narrative. Frank (1997, 1995) is convinced of the saliency of first person illness narratives. Kleinman (1988) pioneered advances in this area, and his more recent work (1997, 1999) advocates ethnography as a medium capable of both communicating the local moral worlds of patients and translating between local patient worlds and the translocal concerns of bioethicists. “Were ethnographers better prepared in ethical reasoning they would be in a nearly ideal situation to project local moral issues and actions into global ethical deliberations, and vice versa” (1999, 73).

The narrative turn in bioethics, whatever the convention, illuminates the moral world of the patient beyond the “sick role” that Parsons made famous (Frank, 1997, 132). Narrative is used by these ethicists to explore the moral dimensions of illness and the propensity of ill people to recite themselves as moral agents engaged in projects of identity construction. “Health crises confront their victims with something to do and things to decide, but, far more profoundly, such crises assault identity—they force their victims to decide who and how they will be” (May, 2002/1970, xxxv). Addressing who we will be is an emphatically moral project for, as Charles Taylor (1989) stated succinctly, “to know who I am is a species of knowing where I stand” (27). The project of narrating illness and identity, Frank (1997) argues, is far removed from the work of hospital ethicists and their tendency to “transform moral aporias – tears in the fabric of lives – into specific decisions” (144).

Ethnographic research on the “moral identities” of the chronically ill is burgeoning (see for example Williams 1993, Townsend et al 2006, Tuominen 2004, Charmaz 2002, Riessman 1990). These studies clearly recognize illness as biographical,
social and moral disruption; chronically ill persons struggle to maintain or regain narrative coherence and moral status. Generally, such studies have demonstrated the ways chronically ill patients manage symptoms (often at considerable physical cost) and narrative impressions to counter the stigma and illegitimacy of illness. “Socio-moral concerns” (Williams 1993), broad “moral demands” (Tuominen 2004), or “culturally valued” practices (Townsend et al 2006) are said to shape the narratives of the chronically ill who reveal themselves as either striving to meet (or at least approach) such standards or disguising their inability to do so. For instance, obtaining a bath-seat becomes extremely significant in the moral identity of a 62-year-old arthritis sufferer who recounts her insistence on this device to favourably situate herself in socially accepted renditions of what it means to be virtuous: independent, clean and fiscally responsible (Williams, 1993).

Portrayals of the chronically ill trying to fit their local moral worlds to wider social discourses of moral value and virtuous behaviour are helpful, insightful and certainly part of the narratives I heard, but I do not believe they tell the whole story—or at least not the whole story of the moral worlds of transplant recipients. Recipients did downplay the narrative of their illness in some settings in order to ‘pass’ as moral inhabitants of a community structured around the virtues of health (see Williams 1993), but very often their struggle, and their transplant, was displayed, highlighted, and framed to validate ethical claims that were not always faithful to dominant moral discourses. Many of the narratives I heard suggested that “healthy” ways of valuing were not only closed to recipients, but also less captivating—*even* as transplant reinstated (in many cases) certain plateaus of health. Frank (1997) intimates a similar sense of creative moral
agency in his discussion of “the potential consciousness of illness”: the potential for illness to enhance the capacity for a new kind of self-knowledge, the potential for illness to stretch the cultural limits of the moral imagination.8 For many of the recipients I interviewed, organ failure and the reprieve granted by the donation of an organ (even if it occasioned other medical conditions) was frequently narrated as the opening to an alternative self, an alternative moral vision – and an alternative moral community of like-minded transplant recipients.

I have felt obliged to provide such an extensive recounting of “non-Kantian” initiatives in moral philosophy and bioethics because even in the highly regarded, deeply insightful and incredibly rich ethnographies of organ transplant there is a sense that an ethical “floor” rather than a virtuous “building” or ethos has predominated. From Lock’s (2002) work on brain-death, to Nancy Scheper-Hughes’ (2001) and Lawrence Cohen’s (2003) expose of third world organ sal- es, to Lesley Sharp’s (2006, 1995) review of the tangled demands of donor and recipient, to Fox’s and Swazey’s (1978, 1992) charge of medical hubris in the field of transplantation -- rights, responsibilities and quandaries have held considerable sway. This is to vastly simplify complex treatments of complex questions. Nevertheless, a clear sense of organ recipients as resourceful moral agents has not come to the forefront in ethnographic accounts of organ transplant.

And while ethnographic accounts have given concentrated attention to the reconstructed identities of organ recipients, they have not, in my view, captured the moral dimension of this project. They tend to focus on the moment of transplant and neglect the longer illness narrative that precedes it. Further, the moment of transplant, the incorporation of another’s organ, is often seen as radically disrupting a previously
coherent and cohesive self (see Sharp, 1995) whereas the idea of a self constantly divided and continuously narrating its unity (see Walzer 1994, Ricoeur 1992, Taylor 1989, McIntyre 1981) belies the idea of organ transplant as ‘radical’ breach, although it is certainly a breach of a different order and magnitude. Even Sharp (1995) (who carefully allows for the conjoined presence of both donor and recipient in the post-transplant creation of self) settles for the static metaphor of ‘gestalt’, suggesting a point at which the work of creating the transplanted self is done. Yet Taylor (1989) cautions: “the issue of our condition can never be exhausted for us by what we are, because we are always also changing and becoming…so the issue for us has to be not only where we are but where we’re going” (46). Finally, ethnographic accounts fail to capture the moral dimension of recipient projects of the self when they fail to consider religion as a source of the reconstruction. If in deciding “who they are” organ recipients are simultaneously discovering “where they stand,” then considerations of the good life, the good person and the good community are endemic to the work of rebuilding their post-transplant identities; while not exclusive, the language, rituals and experience of religion are accepted tools of the trade.

In the following examination of recipient narratives I want to highlight several features of the particular moral project that engaged many of my recipients. As many scholars in many fields have pointed out, health crises assault identity. Like May, Frank, Kleinman and others I concur that this is a moral dilemma; like Walzer, Taylor and Rorty I see this dilemma embedded in moral communities. In keeping with the chronically ill more generally, transplant recipients did find themselves excluded from standard moral communities shaped by the narratives and postulates of health. However, as
contemporary moral philosophy has made clear, “the moral communities we traverse are many. They overlap. They sometimes conflict with one another.” Transplant recipients often worked diligently not only to map a new self but also to locate that self in a new moral community, and religion was part of this quest.

Transplant, then, was frequently narrated as a multi-faceted conversion. The altered body-self, the assertion of evolving spiritual selves, the acquisition of new virtues and the shifts of allegiance from one moral community to another are perhaps best described as conversions. What was the ‘divine spark’ that moved recipients to new stories, new characters, new communities? Myriad moral philosophies document divided moral selves and plural moral worlds, but the mechanism that facilitates or initiates movement between fragments is never really explained. Frank (1997) sees it in the “potential consciousness of illness”. And over a hundred years ago James postulated that it was the religious encounter. My participants, as I hope to make clear, suggested it was their illness experience, their religious experience and their new organs that shifted their moral worlds.

Tears in the fabric of lives

“I wanted to be a teacher. That’s what I wanted: to teach. From the time I was a kid, I knew from back then, I wanted to teach. Grade 4.” By age 18, both Kate’s kidneys and her ambitions are precarious. Regular blood work charts her diminishing renal function as she progresses through her BA and is accepted into the Faculty of Education. And I got sick again. This time with mono. And I was out probably a month and a half. And when I got back, I said to my principal: Would I be better to get out and work and come back?” And he said that would probably be a better idea, cause there was too much catch-up. So I left. But when I went to come back the next year, my grades weren’t as
good as other people’s, so they wouldn’t let me back in. I should have got it in writing. I cried my eyes out over that. I cried and cried. What am I going to do now?

Teaching career denied, Kate joined Gillian in becoming a certified hearing aid technologist. Both Kate and her younger sister Gillian have Alport’s disease, a genetic disorder that affects hearing and eventually kidney function. They have worn hearing aids since they were children. Upon completion of their training they opened a clinic in northern Ontario, renting a house, locating the business in the front rooms, living in the back rooms. Now in her early twenties, Kate’s kidneys have failed. She dialysed at home three mornings a week. Gillian was her assistant, minding both patient and store. Business was abysmal. “We took in about $35 a week. That’s how bad it was. It was awful.” Kate, the energizer bunny, added an evening shift in a local factory to her morning dialysis and her afternoon duties in the clinic.

After her first transplant, Kate stayed in Toronto, accepting a job in a stockbroker’s office. “It had a paycheque,” she recounted. “Back then it was $200. But it was a paycheque, not $25! And I was really enjoying it.” Gillian, now married, remained up north to start a family and continue the business. But pregnancy impaired Gillian’s vulnerable kidney function and she was unable to manage her elevated creatinine levels, a new baby and a fledgling business. It was Kate’s turn to be caregiver -- “and I cried my eyes out. Cause I had to go back to [northern town] and a business that wasn’t going anywhere!”

Disrupted education, career paths closed, job opportunities denied, professional standing jeopardized, entrepreneurial efforts hampered, early retirement, wages lost, independence threatened, obligations owing to friends and family. There was no recipient narrative that did not include one or more of these scenarios. More than sad
tales, the scenarios of organ failure also impede participation in key social narratives of virtue. Health as a virtue, as a matter of right conduct, has deep roots in our Puritan traditions and flourishes in contemporary Western society as a mainstay of individualism; health is the bodily expression and precondition of our revered physical and financial independence (Williams 1993). The epitome of the independent individual in contemporary western societies is the expert, argues Alasdair MacIntyre (1981). The Manager is the stock-in-trade character that saturates modernity with the cultural and moral ideals of autonomy, efficiency and mastery (25-29). Degrees unfinished, businesses floundering, plans waylaid by personal debts or physical crises, professional careers traded for making ends meet, caregivers and social workers, welfare, disability or other forms of social assistance are all antithetical to notions of self-sufficiency and prowess; they are experiences outside, or at the margins of, this dominant cultural script of virtuous lives.

Transplant can never wholly mend these tears in the fabric of professional and fiscal lives. While it gives recipients needle and thread, they sew with a new awareness (of loss, limits, fluctuations and uncertainty) and sometimes with an intuition of alternate moral patterns. For some, transplant comes too late chronologically, or with too many attendant complications and conditions, for old careers to be resumed or new careers to be initiated. The moral status of such “retired” recipients threatens to remain marginal. One strategy to enter the moral mainstream is to articulate oneself as a novel sort of expert -- a transplant expert.

A competitive athlete and a high school teacher, Domenic was sidelined by a massive heart attack in his late thirties. For the next fourteen years all physical exertion –
from walking to lifting grocery bags – had to be strictly monitored for fear of another attack. His heart function slowly deteriorated. His mental health deteriorated also. He described himself as “flat, like a pancake,” performing his teaching duties “on remote control,” reverting from active dad “to a zombie”. Neither his family nor a psychologist could lift his bleak despair. A teaching colleague serendipitously put him in touch with Todd, the founder of a support group for heart attack victims. “It’s like being in a big hole. And you need someone to reach down and pull you out. And everybody else couldn’t do it, but he did,” Domenic related.

In his early fifties Domenic became a heart recipient. He did not return to his teaching career, citing both the infections he fought in the early months of transplant and his susceptibility to infection in the school. In his “retirement” Domenic has become a transplant expert. “Like I’ve become a spokesperson. I mentor people who are waiting for transplants. I’ve talked to hundreds of people,” he told me. “When I started, it was ‘oh yeah, right, sure’ – you know, they sort of paid me lip service a bit.” But when a social worker called him to speak with a very depressed patient awaiting transplant, the intervention clearly made a difference. “So then they started calling me even more. So now,” he told me, with considerable pride, “I’m like one of the team. I have my own parking pass, ID badge and everything now.”

Being part of the team gives Domenic an identity that registers in the wider culture as “moral” in analogous ways to being a teacher: he is important, knowledgeable, professionally validated. Yet (Domenic’s narrative hints) being part of this team makes sense of his illness experience and his transplant identity in ways teaching could not. “That’s kind of why,” he said, reflecting on Todd’s seminal role in the bleakest period of
his life, “that after the transplant and everything, I’ve become a spokesperson.” His success as a mentor has led to membership on federal councils dealing with transplant policy. “I’m recognized in certain ways, and that recognition gives you significance,” he acknowledged. But it is, he qualified, “a different kind of significance. It’s like helping others helps yourself. You know? It’s a very symbiotic kind of thing.” His comments suggest that becoming a transplant expert addressed possible moral censure around his ‘early retirement’ and communicated a post-transplant sense of who he was and where he stood.

Not all organ recipients retire early. For some, disruptions to education and careers are navigable; transplant is a bridge to the resumption of successful, independent paths and the attendant merits they afford. However, in a number of cases, the experience of organ failure meant lauded social roles were revived with post-transplant discernment.

Steven was diagnosed with the early signs of liver failure while an undergraduate. His liver function declined surprisingly rapidly making him a candidate for transplant at just twenty-five. The transplant (aside from initial complications from infection) was a success. Steven relocated to Toronto, completed an MBA, and some six years later when I interviewed him was employed in a managerial role in a large corporation. Slim, calm, soft-spoken and moderate, Steven was unusually loquacious when I asked him if he felt changed after the transplant:

Do you feel changed? I think you feel appreciative of what you have. You know, it’s easy to get caught up in everything and I know I still do. Sort of the pursuit of—whether it’s going to school or working and doing all that. Going and going and going. Striving for things. I think now, you know, you sit back a little more and appreciate the life you have and don’t get caught up in the pursuit of things that might be a little more frivolous…. 
I enjoy what I do, but I know that I can go out and get a job somewhere else. And I don’t believe in an extravagant lifestyle. If all of a sudden I get a job that pays me less, it’s not going to make or break me. That’s why I try and live a little bit below my needs, so I have that flexibility. The flexibility’s important to me just because I enjoy the [extra-curricular] things I do; a lot of the things that I do don’t demand a lot of money. So I enjoy my work and it pays well, so I’m glad that that sort of comes along with it, but it’s not reason enough to make it the centre.

I had the option when I took my MBA to chose which industry I was going to work in. And I could have gone into an industry where people typically work 60, 70, 80 hours a week. A lot of people I know do work those type of hours. But again, I chose not to. Again, because I want to be able to live now. And I’ve had the conversation with people I went to school with and they chose the other route. They said, ‘I want to work hard for the next ten or fifteen years of my life so that then I can enjoy things.’ Again, it’s their perspective on it. I’m not willing to give up 10 or 15 years of my life right now for the ‘promise of’.

In Steven’s narrative an alternative moral code competes with the canonical reading of fiscal independence and efficient productivity as paramount. What Steven counts as virtuous lies somewhere between striving for proficiency and living for the moment. In this he complies with a traditional description of virtue, its articulation as a mean between deficiency and excess (see Williams 1993, MacIntyre 1981). His post transplant character is not entirely newfound. “I had a bit of that to begin with,” Steven related. “It’s just now—it helps me to back it up, to perceive it.” Transplant has made possible both the things he enjoy (sports, time with friends, personal relationships) and the career he is pursuing; however, when he narrates how transplant has impacted his life, he speaks of his clearer understanding of where both of these fit in ‘a good life’.

At several points in his narrative, Steven distinguished himself “from people who have been sick for a longer period of time” and I have come to see the relevance of this distinction. Long-standing tears in the fabric of lives (especially those existent since childhood) bleed differently than sudden rents in healthy selves and are mended
differently in the post-transplant tapestries of these moral agents. In such cases, illness is not narrated as a “fall from grace” to the tenuous moral margins of dependency and non-productivity. The margins are where they began. And the process of constructing themselves as moral agents didn’t await their transplant; it began long ago. Many entered the moral mainstream much as Domenic did – they became experts, experts at illness.

“I’ve grown up in the system,” Jeannie explained. The thirty-year old woman sitting in front of me was as trim and petite as a fifteen-year-old girl and as wary and battle-weary as an aging general. At just over a year old, doctors realized that her kidneys had not grown. Failing to comply with doctor’s expectations that she would die before she was two, Jeannie spent her pre-school years on hemodialysis at a time when dialysis for children was itself in its infancy. Rising through the ranks, she had her first kidney transplant at seven. An unqualified failure, she never left the hospital with it, although she did spend several months confined to isolation as doctors worried about her pharmaceutically suppressed immune system. At eight she had her second transplant. It allowed her freedom from dialysis, but the effects of the early immuno-suppressants on her pre-pubescent body were so extreme that she shed few tears when the transplant failed within five years.

For the next eighteen years she resisted (sometimes strenuous) medical advice to have a third transplant. She had made her way through high school and was progressing toward a social work degree, dialysing variously at home and in a variety of clinics, sometimes battling, sometimes forming allegiances with the diverse doctors, medical boards, nurses, administrators, social workers and therapists she has encountered. In her narrative, the intensity of these relationships parallels those found in nuclear families.
Now, at thirty, a spate of recent firefights with a number of debilitating and mystifying ailments has convinced her to try again. Her father had been tested and found to be a suitable kidney donor. However, the impending transplant was causing Jeannie more trepidation than relief.

There’s always been this fight…on the need to find the line between focusing on it [her illness] and being the victim, and it not being the focus, don’t talk about it, don’t be obsessed by it.

You don’t want it to be your focus, but…. Like now, looking at transplant…

It’s been a big part of my identity for 17, 18 years. I’m a high profile patient. I am the ultimate survivor. I’m the one that’s been around the longest, in a lot of cases. In terms of my attitude, in terms of—I’m very aware of the expectations on me, coming from staff and coming from family, or whatever. That I will give back and I will try to help people and I will do well. There’s huge expectations on me. Because of who I am. And because I’ve been in the system so long.

The threat transplant poses to Jeannie’s identity is not the spectre of a foreign other invading her embodied sense of self, but a moral threat to her identity as a successful patient. Transplant imposes new ethical expectations, expectations that grow out of her warrior status and the moral community she is part of, but expectations she will face largely outside the confines of that moral community, however embattled she has sometimes felt there. Uncertain who she will be when she is no longer “a high profile patient”, “the ultimate survivor”, Jeannie feels uncertain about her ability ‘to rise to the occasion’ of transplant’s moral tasks.

I do not know the next chapter in Jeannie’s story. But in the narratives of others chronically ill since childhood, ‘rising to the occasion’ of transplant frequently meant altering or abandoning identities as successful, competent and knowledgeable patients embedded in a “system” (or moral community) structured--very hierarchically!--around an ethos of caring for others. It is perhaps not surprising that an ethos of care comes to
dominate the reconstructed identities of such recipients in their post-transplant milieus.\textsuperscript{12}

I could recount the extensive social commitments of many of the recipients I interviewed (especially those ill since childhood), but Kate’s “energizer bunny” nature particularly underscores this point:

AM: So you’re doing the animal shelter, radio station, Canadian Transplant Association, Transplant Dragonboat team—

And I’m the volunteer organizer for the church. Volunteer for the Kidney Foundation. Volunteer bartender at the Legion. And I’m also with the local television station; I’m a volunteer there. (I wanted to learn the TV camera. And then they didn’t have anyone to do interviews -- they sent me in front of the camera!)

The business Kate and Gillian began so many years ago no longer makes $35 a week. Ten years of perseverance paid off and the hearing aid clinic now provides a comfortable income. However, this accomplishment is barely a footnote in Kate’s story; what takes centre stage in her narrative and her identity is her on-going service to others and the solidity, community and moral direction this provides her.

Some recipients combined this service work with regular employment. Others combined it with disability payments or other forms of social assistance. I had wondered about the propriety of devoting such extensive time and energy to volunteering in the absence of paid employment. “Think about it,” Kendra said to me, in regards to another prolific volunteer, a fellow kidney/pancreas recipient who had suffered since childhood from diabetes and its complications, he wasn’t as lucky as me. He wasn’t able to complete his education. He hasn’t been able to build up work experience. If he went to work now it would be for minimum wage, probably without benefits. And he would have to give up the security of drug coverage and other things, and if anything went wrong with his transplant where would he be?

Kendra was learning firsthand the vagaries of such a predicament. Her pancreas and kidney transplants had fuelled the completion of her master’s degree in art therapy.
She had moved to Toronto to take up a job in social work (like many others combining her professional life with a full slate of volunteer obligations). When I interviewed her she was positively aglow with the possibilities life held for her. And then the unthinkable had happened. Her new pancreas had failed. Her insulin levels were more uncontrollable now then they had ever been in her life. An insulin pump was recommended. Her medical plan at work did not cover such a devise, nor did provincial medical insurance. Her salary couldn’t afford it. Her choice seemed to lie between relinquishing optimum healthcare or relinquishing the very hard won status of social work professional in favour of a patient identity that would give her wider access to healthcare funding.

The issue of (relatively healthy) transplant recipients who remain on social assistance is a puzzling and pervasive one for transplant professionals. But the stories here, of both the employed and the unemployed, suggest that moral identity is a significant dimension of the issue (without discounting the pragmatic dimension of transplant’s vagaries and the structural dimensions of public healthcare funding).

Financial and physical independence, expertise and productivity are “healthy” virtues, practices that are, frequently, inaccessible goods in the lives of those who have been ill since childhood. Organ recipients from this background have often been socialized in a distinct moral community that emphasizes virtues of care and compassion. Post-transplant, many of these recipients juggled a collective vision of social altruism with the principles of personal achievement. Even in the narratives of recipients who were very much socialized by the ethics of “healthy” individualism, the experience of organ failure is a tear in the fabric of life that cannot be satisfactorily stitched by simply adhering to old moral patterns. The dominant moral demands of independence and expertise were
not abandoned, but were moderated, reworked or embroidered by these resourceful moral agents.

_Tears in the lifecycle_

In addition to defining key moral practices, health also imposes an authoritative historiography that shapes both scientific and moral discourse. The familiar and proper chapters of life follow the development of the healthy body: infancy, childhood, youth, adulthood and parenthood, progeny and old age. Each stage enjoins a narrative frame that is normative, in both a descriptive and a moral sense. The markers that define each stage are ethical as well as physical achievements; one need only consider the full resonance of “being an adult” to appreciate this. Conversely, to deviate from the lifecycle script implies deviance.

Organ failure very often meant a departure from the tidy unfolding of physical development and its attendant social expectations. Recipient narratives revealed the moral ambiguity and existential angst inherent in such detours.

AM: So they told you at twelve that your kidneys were about to fail. And that you had a limited time before you’d have to be on dialysis?

Adele: Yes

AM: And were you able to go to school?

Adele: Oh yeah. I did that, but my mother had to pick me up and drive me… My parents knew that I was never going to get better but I didn’t know. And then they’d pick me up from school. There isn’t a lot of exercise I could do, different things like that. I felt it hard. ‘Cause Grade 7 is just starting everything. Teenage years: everything is mapped, your dreams, your goals, everything is just… It changes your whole life—you’re on a new road, right? It was really hard for me to accept all that.
There is a new road but no roadmap when illness disrupts the familiar trajectory of development. The disorientation Adele felt at twelve found no resolution in transplant.

In the early 1970s Adele was among the first juvenile transplant recipients and transplant technology was itself still developing. Between the ages of 15 and 18 three unsuccessful kidney transplants were performed, the third ending in a violent rejection that threatened her life. Dialysis, both peritoneal and hemo, was the path Adele travelled on throughout her twenties.

For many I spoke to, detours in crucial teenage years circumvented the conventional lifecycle progressions of dating, mating and marrying. Jeannie told me that she had recently joined the outdoor club at her university in an effort to “meet some guys.” “Growing up in the system” has paradoxically cocooned her and prematurely aged her. “It’s another wrinkle,” she told me. “I’ve actually never had a serious relationship. I’ve dated a bit, but—again, it’s that dichotomy between being heavily mature and fourteen years old.” Adele, too, has found traditional scripts unworkable:

AM: You didn’t marry your boyfriend, but you’ve dated him for a long time?

Adele: I met him when I was 18. I’ve known him for thirty years. Well, it’s just that I have such a complicated life and I didn’t want to complicate it more. I just didn’t feel it was me. I didn’t feel I could be put in that situation…he’s more like a friend than anything else now…. He’s pretty upbeat and crazy and we have a lot of fun. His family is wonderful. I’m very fortunate that way. He said he wanted to get married, but I said no, it wasn’t for me. I didn’t feel I could handle that situation, dealing with all my health problems and different things…

One problematic arc of the lifecycle curve, especially for women, was the issue of procreation. Pregnancy is a risky venture for women with transplants—it carries a threat to mother, child and especially to the transplanted organ. The threat varies according to the health history of each woman, but it is invariably present. For those female transplant
recipients who ventured forward, ‘motherhood’ allowed them a familiar, socially sanctioned sequencing of their lives. For those who did not, alternate plot configurations were both a narrative and a moral necessity. For Kate and Gillian, the sisters with Alport’s disease who have known and participated so intimately in each other’s transplant stories, divergence on this lifecycle construction forged distinct moral selves.

“The first thing we’re going to do is schedule you for a tubal ligation.”

In Toronto for a biopsy to determine her remaining kidney function, those were the words with which the nephrologist greeted 21-year-old Gillian.

I’ll never forget it. I was in his office—I did not know this man, he’s got my chart, he’s not even looking at me…. And my eyes popped out of my head. I’d just got married. I don’t even remember what I said, cause I’m not the person I am now, but I probably looked crushed. But anyways I went back to Dr. S— and I said, ‘you find me another doctor. I’m not going back to him.’

Dr. S—, he says, “if you’re going to have a family you should do it soon because, gathering what’s happened to your sister…”

Louise was born in the first year of Gillian’s marriage. The pregnancy was a difficult one, increasing weight and fluid retention escalating her blood pressure and compounding her unstable kidney function. She escaped dialysis for a few years, but in due course became a peritoneal patient, a transplant candidate, and eventually a transplant recipient.

It was probably the first words out of my mouth when I was looking at the transplant because I really, from the minute I held Louise, I wanted to have another one. I mean some people are just born to be mothers (not that you have to have kids). But I really… when my mum was living and we used to watch the Walton’s—I just really always wanted to have a family.

Almost straight out of this thing I asked my transplant co-ordinator, was it possible? She said there’s been a few and she figured I’d have to wait almost two years…
Two years later, of course, I was still thinking of a little person.

Gillian’s husband was reticent. They knew of post-transplant pregnancies that had resulted in lost babies, lost organs and lost mothers. He insisted that the risk to Gillian be less than 10% as determined by a trial adjustment of her immuno-suppressant regime and extensive testing.

The obstetrician asked me, “Why do you want to do this?” And I said, “I need to know if I’m going on from here. I know I’m a mother, but I need to know am I finished mothering little people, and that’s fine if that’s where it is.” I said to him, “I don’t expect you to understand, you’re a man, but women have to know.”

The results of the testing were positive and the obstetrician pronounced the risk to be less than ten percent, but warned:

“You know, Gillian, not to burst your bubble, but you had so many problems, so much surgery, you’ve had a transplant, you’re still on some drugs, it might not happen. You might not be able to conceive.” And I said, “OK. That’s between me and the God upstairs….” I said, “let’s go on faith with this one; if it doesn’t happen, it’s not meant to happen.”

Anyways I walked back in six weeks later: “nah, nah, nah!”

In the midst of the elation, there was the painful recognition of her sister’s exclusion from this customary mantle of womanhood. “When I got pregnant with Eamon it was so hard to tell Kate. I just dreaded telling her,” Gillian related, She had got married. I just didn’t know how I was going to tell her. And she kept up a brave face the day that I told her but when I talked to them later, I knew that she’d gone off and had a really good cry. I mean, she was happy for me, but the fact that… I don’t know how old she was by that time, but basically for her—three transplants, the punctured lung, there was just no way that a child could arrive. Really just not. Life’s not fair.

Gillian’s second pregnancy was high-risk, necessitating weeks in hospital in Toronto separated from both her husband and her daughter. But the risks to her baby, her transplanted kidney and herself were safely navigated. Eamon was ten years old when I
interviewed Gillian. We spoke on a Saturday in her home, a beautiful log structure on a rural lakeside lot that her husband and her had worked on steadily for years. Our interview was punctuated by the comings and goings of her family as they went about their weekend errands. Gillian’s life was clearly centred on her children. The arrival of her children was also central to her transplant narrative for it channelled Gillian’s chronology outside of illness into broader, well-established, cultural currents.

I mean, things for Kate and I are marked—I can tell you almost anything you want to know from 1980 to 1990 because it’s marked by who had transplants, who was on dialysis, who was whatever.

But after ’92, after Eamon was born, don’t ask me too much because life starts to go on the way it was supposed to.

Kate has, however, had to dig her own channels. She has had to dig with the awareness of being outside standard chronologies, outside customary attributions of feminine value, outside even her own desires.

Gillian’s been, uh, she’s been lucky. I do know—I mean, I never told her this: when she came and told me she was pregnant with Eamon, I cried my eyes out. I was happy for her. With her. But scared to death. And I was jealous. They told me: “three transplants, don’t even think about kids.” And I always wanted three or four kids. Always.

And I was really, really upset that she could have it and I couldn’t.

And, I have my dog. And I have eleven kids: my nieces and nephews. I can borrow them for a while; send them over.

But you know, that was what really—that’s about the only thing. Other than, I said my one dream was to be a teacher and the other one was to have my own kids. I think that’s my only regret, is not to be a mum.

But somebody said to me, “You know, Kate, maybe you were meant to be like this so that you could get out there and help other people, charities, and that side of life.”
Tears in the lifecycle threaten coherency and legitimacy. For many transplant recipients, validating an atypical chronology and telos has been a risky, hard and painful labour.

*Tears in bodies*

Healthy bodies are virtuous bodies in another pervasive and patent way: they afford the aesthetic ideals of beauty, gracefulness and nobility. The aesthetic body is tethered to our moral understandings. As Wim Dekkers writes,

> We can judge any posture and movement from a normative perspective. These judgements assess whether or not a particular posture or movement is effective, adequate, harmonic, decent, etc. and also whether it is ugly or beautiful, and even (morally) right or wrong (1999, 117).

Dekkers identifies two dominant strands in contemporary assessments of the body. Citing modern pursuits of body-building and athleticism, he notes “certain aesthetic conceptions of ideal bodily form” that enforce characteristic norms, norms that exclude the disabled, the aged and the ill. “Health has become more than an instrument for survival, more than a biological imperative. It has become a social imperative: it represents prestige, social election, and social differentiation” (1999, 125).

The body as aesthetic object, with the moral judgments of wholeness, soundness and strength that sculpted muscles, powerful gaits, and taut skin intone, challenges transplanted bodies, frequently pierced, slowed and scarred by the progression of their organ failure as well as by their transplant and the impact of immuno-suppressant drugs. “They’d been in there,” Kate related, staggered, “kidney in, in July. Out in August. Parathyroids out in September. My spleen out in November. It was just—can you not put in a zipper?”
The second dominant strand in contemporary assessments of the body, Dekkers argues, is the “objective body” championed by modern medicine, the body conceived of as a utilitarian and plastic container with no affinities to the human contents it contains. It is a body without aesthetic qualities, a body divorced from attributions of beauty, uprightness, warmth and grace. The epitome of medicine’s “objective body,” Dekkers states, is the transplant body:

The world of organ transplants is pre-eminently a world of technological enterprise. As a result there is an increasing tendency to consider the human body as a thing that can be transformed and manipulated, as a constellation of organs that can be replaced at any time we think it necessary. It is increasingly difficult to see the human body as a subjective lived body, as a body with its own integrity and gracefulness. (1999, 125)

In prevailing cultural assessments, the bodies of transplant recipients are morally suspect. Ravaged by illness and operations, they are excluded from cultural norms of grace and beauty. Rearranged by transplant they are rendered unnatural; marvels of technology at the expense of integrity.

To become a virtuous body in the face of hegemonic discourses and imagery of the body healthy, integral and upright is no mean feat. It requires what Dekkers calls “an aesthetic subject” – a perception of the beauty, richness and worth intrinsic to the lived body-self “because the body reflects (or even is)...personal history lived” (1999, 125). It requires an awesome faith in the dignity of one’s body and one’s self.

In the years after her kidney transplant, Maxine (a lifelong diabetic) encountered circulatory problems that necessitated the gradual amputation of her toes, “from the left foot to the right foot, and back and forth, back and forth,” culminating, finally, in the below knee amputation of her right leg. The World Transplant Games were in
Vancouver the year Maxine’s leg was threatened with amputation; she attended with the doctor’s warnings and instructions ringing in her ears.

So I took all this into account and I made it OK at the Games. I did not swim. And it was a very difficult Games for me. And I couldn’t go, emotionally I could not go, to the swimming pool. I just knew I would cry the whole time and I didn’t want anyone to see me doing that….

I was always on the verge of tears because I was mourning what wasn’t gone yet, beforehand. I was sad that I wasn’t in the pool. And I was sad, I was mourning, what I hadn’t lost yet. But I knew the loss was imminent.

When the loss became realized, Maxine struggled through the mourning, the prosthesis and the physiotherapy, gradually regaining her equilibrium mentally and physically. “But I knew that if I was really going to live with this,” she told me, “I was really going to have to like me, to be very comfortable with who I was, before I could expect others to be comfortable with me.”

She is not sure how she came up with the stratagem she did, but when it occurred to her she was intuitively sure of its rightness. She booked a holiday at a nudist colony. “Now,” she related,

I’d never done anything like this before, nor did I know anybody who had. So I had to search a bit. Because I wanted to be sure what I was getting. You know, what rules they had, what atmosphere. I looked at them very closely.

She finally settled on a location in Ontario. She told people only that she had booked a holiday and didn’t divulge her destination. And she told me of her slow and shy reveal, wearing track suit one day, shorts the next, a bathing suit followed and finally, “feeling sillier with my clothes on than off,” stepping out as she was. It was, as she had suspected, the journey she required. The experience left her intact, ready to face friends and family more openly, ready to assert a self virtuous not only ‘in spite of’ its missing parts, but precisely in its missing parts.
If her trip to the nudist colony was not a tale Maxine told many, it is a tale those who know her would instantly recognize as hers. “Mad Max,” Kate calls her, a reference to her legendary openness and fortitude. Even after the amputation, Kate related, “Maxine would get in that pool. And she would come in dead last. But she would get the loudest applause. You know?” Maxine has been selected Canada’s flag-bearer in the Games’ opening ceremonies. Other transplant athletes have awarded her their gold medals (“that’s how I get gold medals!” she laughingly told me). Receiving this medal was an honour, Maxine explained, because I know he’s thinking—I know the feeling that comes from it. All kinds of feelings. It’s a feeling of love and friendship. It’s a feeling of hope. It’s a feeling of appreciation for life. And it’s a feeling of wanting to share. It’s a symbol of a whole bunch of all the good things we really know are precious in our lives…. We call it the spirit of the Games actually.

If Maxine is the darling of the Games (and wider transplant circles) it is, I would argue, because she makes visible the sometimes invisible dilemma that faces transplant recipients more generally: the dilemma of constructing their torn bodies, disrupted lives and atypical chronologies into an ethical narrative, a moral identity and a vision of the good life despite the dominant cultural accent on health as virtue. Much of the rhetoric of transplant suggests that receipt of an organ will place recipients securely back in the fold of a more pervasive understanding of “the good life” (i.e. a “healthy life”) but most recipient narratives were circumspect about the tenets of this maxim and convinced of their place in an alternate moral community. 16

“When I was ill,” heart recipient Jim explained, my friends pretty much stayed around because, like everybody else, they thought I was going to die. We’re all about the same age—a 45-year-old friend and they thought he was going to die. That was kind of scary. So pretty much the same friends then.
But after you get your heart, then they sort of drifted away. It’s like I scared them or something. Or they expect something different from you. And you’re pretty much the same person, but you’re not the same person. I have friends now who I really admire who I would never have known if I hadn’t had a heart transplant.

AM: so is it you or is it your friends who are reaching out for something different?

I think it’s me. I really do. I’ve thought a lot about that…. You certainly change yourself and the problem you have to deal with at first is--you expect everybody else to change. You expect everybody else to feel the way you do. And they don’t! I mean—they couldn’t…. I mean, it’s very hard. And it’s almost mean to try to force people into understanding. My wife was even—didn’t get it; but I don’t expect it.

And it’s just—well, up at the Transplant Games there were 3000 of us, 3000 transplant recipients, all kinds. And it’s like we become friends right away. There is a bond. You know? And you stay in touch with most of them forever….

When I tried to pinpoint what it was that transplant recipients shared and others didn’t, Jim did his best to elaborate:

It’s ‘oh gosh, what were you worried about!’ I mean, you can’t waste a lot of time worrying about stuff that’s so little or non-consequential. Actually, when you come down to it, there’s not all that much to worry about, not for just regular people, for us (maybe for the prime minister of Canada). There are just so many other things. And I think that that’s the thing that’s most baffling, particularly for my wife. She’ll worry and worry and worry about the IRAs that we’re buying, and I just don’t care! You know?

AM: were you a worrier prior to all of this?

Oh my! Nuts! I worried about everything. I was not particularly even-tempered. And I worried a lot. Now it takes an awful lot to upset me because…I don’t know, Arlene, maybe when you know you’re going to die and then you don’t, it changes your outlook.

“I think,” Jim concluded, in his affable and self-depreciating way, “most of what I’m saying is about as clear as mud.”

Initially, I found recipient references to transplant’s spiritual significance, the spirit of the Games, their dawning spirituality, spiritual bonds or spiritual encounters about as clear as mud. It was only when I realized that “spirit” had some covalence with “character,” and only when I framed these assertions in terms of virtue theory that their
interrelation, frequency and urgency began to make sense. Recipients’ transformed bodies, lives and identities (rooted in organ failure as well as the promise and unpredictability of organ transplant) were simultaneously transformations of “where they stood.” In so many of these narratives the language of spirituality, the force of spiritual encounter and the piety of spiritual practice were what best described, initiated and sustained newfound moral character and community.

*A catalogue of virtues; a compendium of religion*

That’s when my life begins—with my transplant! I’ve changed my whole outlook on life! I look at things differently!

AM: you mean this idea that there’s things happening for a reason, or that there’s impulses that you need to respond to because even if you don’t know where that message is coming from you know it’s important?

Yeah. Exactly!

AM: you didn’t previously think that way?

It would hit me, but I never thought about it until I had my transplant. And I’ve done a lot of reading. Deepak Chopra…all kinds of different stuff like that.

AM: stuff you wouldn’t normally have picked up?

No, not really. I don’t think I would. But it was like, um, ‘I want to change my life.’

The “positive” life generated by her liver transplant radiated in Sylvie’s face and demeanour. She seemed younger than her fifty years by a decade or more. Soft, vulnerable, she was still speaking in exclamation points, still quickly moved to tears, some twelve years after her transplant. It was hard now to imagine her azure blue eyes clouded and yellowed by liver disease.
Sylvie had little regret for those parts of her life swallowed by liver failure. Even the dissolution of her first marriage shortly after her transplant was narrated as a segue to a beginning rather than an ending.

He didn’t see things the way I did anymore. Yeah, it was really different.

AM: Oh, so in part the transformation you were feeling, he couldn’t come along with it?

Yeah. It was sad in a way, but it had to be. You know? I was like a butterfly opening up, taking off! And I didn’t want to feel like I was still down here, in a cocoon….

It’s like a rebirth. That’s why I was watching the [televangelist] church! It was like a rebirth of everything! They say something negative always turns into a positive and that’s exactly what happened. It was like get rid of the liver, get rid of the negativity in your life, and—look at this: the new liver. And now everything’s fresh and beautiful.

Few people were as liberated as Sylvie from their pre-transplant selves. Many spoke of the rupture with previous states, abilities and statuses with sorrow. “I try not, actually,” Jim told me, “I try not to think about the fact that my old heart sat there beating for fifteen minutes, like it didn’t want to go away.” Domenic still felt the sting of his lost athletic career: “The bad thing was losing all my athletic ability, you know? I couldn’t see how I could ever get over that. But I did. Kind of. But it never went away because I always wished that, man, if I could only just start running….like that never went away.”

However, what many shared with Sylvie was the sense that their transplanted self could generate a more meaningful life—if one was willing to let go of who they had been and consciously engage who they now were. Domenic read his attachment to his athletic prowess as:

sort of like a fault within myself too. Like I gained so much significance from my athletic ability. That was me, right? Whereas when afterwards I had to put it in other areas…You do move on, you know. We did. And then, eventually, after transplant, then you look back and you’re like: ‘Geez, everything happens for a reason. Everything happens for a reason.’
Maxine also lamented the many losses her failing health had entailed. “I wish that I could still do the things that I would like to do, such as cross-country skiing. Running. Running along the beach, running through a field. Riding a horse. But as I said to you before too; I’ll just reiterate this;” she paused and then continued, enunciating every word very clearly:

I have gained so much because I’ve reached out (and because it has come my way without even reaching out) and I’ve recognized it: that I am not a person who is without.

Clearly, accepting the losses of organ failure, moving into the possibilities (and complications) of transplant is a somewhat compulsory exercise. But it was not only necessary, these transplant recipients claimed, it was also good to “reach out,” to recognize and move toward this new self, whoever it might be and whatever its purpose. Their narratives were rarely stoic; more often recipients claimed the discovery and realization of their transformed self as a quest.

They were also clear that the process of negotiating who they were and where they stood was a continuous one; transplant was a vital turning point, often the very thing that let them keep narrating, but it was not the end of the story. Many of the recipients I interviewed had had multiple transplants. And frequently either their transplants, their drug regimens or their organ failure had produced such a litany of health issues that they generally perceived themselves to be outside what Frank (1995) calls “standard illness narratives” of resolution and cure. With characteristic bluntness, Jeannie set the record straight:

Transplant’s not a cure. The system very much used to [say], “You’ll get your kidney and everything’s gonna be fine.” I still think there are people in the system who haven’t had their first kidney yet and that’s their modus operandi. They’re like, “I will get my kidney and everything will be fine.” And you’re like [snort]: “You’re in this for the long-haul sweetheart.”
Being in it for the long-haul was, for many, an identifiable kind of “practice.” Navigating the instability of their bodies, the regimens of drugs, and the invasions of medicine was both an embodied practice (in Bourdieu 1977 and Mauss’ 1979 sense of habitus) and a social practice recognized by other transplant candidates and recipients. The latter sense corresponds to Alasdair MacIntyre’s (1981) evocation of “practice” as central to the conceptualization of virtue. Practices are said to generate their own rewards, goods internal or intrinsic to such practices. Particular practices provide, MacIntyre argues, “the arena in which the virtues are exhibited and in terms of which they are to receive their primary…definition” (172). A virtue then, he states, “is an acquired human quality the possession and exercise of which tends to enable us to achieve those goods which are internal to practices and the lack of which effectively prevents us from achieving any such goods” (178).¹⁷

Not all endeavours are practices, MacIntyre qualifies – farming is, planting turnips is not – however, “the range of practices is wide: arts, science, games, politics in the Aristotelian sense, the making and sustaining of family life, all fall under the concept” (175). Medicine would no doubt qualify, and (if one focuses on patients rather than practitioners) medicine’s correlates – illness and healing – arguably qualify as a practice to which one can be initiated, at which one can excel, from which internal goods can be extracted, the achievement of those goods benefiting the whole community who participate in the practice (MacIntyre, 1981, 169-189). As with other arenas of practice, “chronic-ness” patents its own virtues, keys to wrestling from illness and medical intervention whatever ‘goods’ lay within. Perseverance, discipline and courage were the virtues these transplant recipients most often cited.
“One thing I’m lucky and fortunate: when things happen to me they happen really badly” [on this point she was not exaggerating: the failure of her first three kidney transplants, a decade on dialysis, her fourth transplant at thirty years of age and a decade of transplant health before it too failed, the resumption of long-term dialysis and its attendant complications] – “but,” Adele announced with considerable aplomb, “I bounce back.” Such resiliency was not inevitable; persevering was both self-cultivated and lauded by others. Adele attributed her success to her steady adherence to her faith and her resolute preference for optimism.

People will say, “you looked like you were dying last week; you looked terrible. Now you look like nothing happened to you!” But again, I think it’s spiritual. I think it’s just the strength I get from above.

My grandmother was a churchgoer in the Anglican Church and my parents took me to Sunday School. My mum was a Sunday School teacher. Dad was a warden and we’d go to church every Sunday…. The idea of faith in God being there (or stronger power, whatever you want to call it), that’s my belief. There is a stronger power and there are people watching over us—not people, but angels watching over us….

My faith has gotten stronger over the years. Like you could go the other way—“well, all this is happening to me” and get very negative and want to leave it all. But in the end you need it. When you’re all alone and there’s nobody there, you need something to reach out to, to talk to, to know that you’re not all alone. I mean, if you’ve given up on all that then there’s a horrible hole, an empty feeling inside, so I’ve never done that.

That’s my feelings, right? And it does work. And laughter. Laughter has been one of the most positive things in my life. People tell me, “Adele, how do you always keep such a happy disposition when you’ve been through so much?” But what gets me through all these things is looking at the bright side. And my grandmother used to say, “Adele, people wake up in the morning and see the sunshine and be thankful.” So I think of that.

Many of the recipient narratives I heard seconded Adele’s inculcation of spiritual strength and a sense of humour as vital aspects of their chronic practices. But the ability to persevere—in their precarious health, their faith and their optimism—was constantly at risk. Most of my recipients recounted moments of wishing they hadn’t gone through
with the transplant, times when they questioned God’s goodness, and extended periods of clinical depression. Virtues, MacIntyre (1981) observed, must correspond and reinforce one another. Frequently, in order to persevere, another virtue needed to be acquired and exercised: recipients needed to be disciplined. Certainly, a sense of discipline governed their immuno-suppressant drug regimens. There was no greater vice, and several were emphatic on this point, than failing to preserve the donated organ by disregarding directives around medication. But the notion of discipline extended beyond medical directives to preserving aspects of the self.

Several felt the need to “keep moving” and maintained a disciplined commitment to exercise and sports. “I try to do something two or three days a week—minimum,” Jeannie told me.

You know what, if you talk to anyone who’s long term the difference between health and not being healthy long term is exercise.…. AM: I noticed when you were talking how important you found it

It’s in your head. But they’re also finding research now that the difference between bone density and all that long-term dialysis stuff is keeping those joints moving…. I’m fairly coordinated and I love it. But definitely there’s days, especially in the last year and a half when you force yourself to go out for a walk or whatever. When you feel like hell, you’ve got to get out there. You’ve got to keep moving.…. The discipline of exercise is a virtue that perpetuates goods internal to the “chronic” practice it is part of. It nourishes both physical and mental health, and it embodies perseverance—one literally “keeps moving”. It is also a badge of honour instructing others in both “chronic-ness” and the virtues pertinent to it. Transplant Games and Dragonboat Teams are the social bearers of the virtue of disciplined movement.
Several also felt the need to discipline their emotions. An “even keel” is hard to maintain in inclement weather; yet “chronic-ness” is precisely the condition of unpredictable seas. Recipients referenced the emotional instability caused by bodily processes in disarray, the volatility of chemically driven moods, and the erosion of equilibrium due to worry and uncertainty. “Sometimes I dip very low and sometimes I am volatile,” Maxine related.

I don’t even see it coming. I try to practice telling myself “before you react, just stop. Think of the consequences that your words would have.” And I have to understand that it might be blood sugar levels, it could be part of my depression, it could be my diabetes going up, down and everywhere. It could be any of those things. I know it is any of those things. And sometimes it could just be that I’m on a very short—what is it?—loop….

It’s something that I’m still, I wouldn’t say struggling with, but still teaching myself how not to allow myself to get to that point.

A disciplined attention to one’s moods and reactions was often considered commendable, an aid to resiliency and a virtue crucial to the smooth social workings of transplant and patient collectives made up of similarly “volatile” characters in frequent contact with the very controlled moral community of biomedicine.

The practice of “chronic-ness” also required courage. To be in it for the long-haul meant being open to risk, familiar with pain, and vulnerable to medical authority. Recognizing that one was in it for the long-haul meant conceiving of a future as potentially difficult and threatening as one’s past. Such knowledge meant that discipline and perseverance were insufficient virtues without the judicious addition of courage.

“Now, my next possible crisis, barring heart problems, would be loss of a limb,” Teresa told me matter-of-factly. The diabetes that had caused her kidney failure continued to pose health threats even as her transplanted kidney thrived.
I very possibly will be in Walt’s [her deceased husband’s] boat one day. I have neuropathy in both feet. And that’s progressing rapidly. I take really good care of my feet and legs, but…. I’m going to have a stairlift put in now before I might need it. Cause when Walt lost his leg we were in a two-story townhouse. That stairway was not able to have a stairlift put in. And the front entrance was not able to be made accessible….

I have a stone in my bathroom. One of those stones that you hold, that’s your hand shape, and it has the word ‘Courage’ engraved on it. That stone I bought for Walt. Some of the things he had done, when they were trying to debride his heel, couldn’t be done under any anaesthetic. And I got him that stone because he went through hell. And I’d never seen a more courageous person being…tortured. And I got him that stone to hold and squeeze to death. And that stone I’ll keep for the rest of my life to remind me of his courage.

Here Teresa’s voice faltered. She stopped. Caught her tears. “And,” she continued shakily, “for my future. That, um, I may need that courage.”

Many recipients discovered that a particular kind of courage was needed to persevere in their never-ending rounds with doctors “who knew better” and nurses “who ran the show.” The longer the chronic practices of health crises and medical intervention continued, the more recipients sought the courage to assert themselves.

“You know,” Kate confided, “if you could visualize me in high school, I was a wallflower. I didn’t say boo. In fact, in public school if you made a face I was crying my eyes out and my sister Daria would come and beat you up for me. I was the biggest baby!” I express my disbelief; I marvel at the transformation.

It was just, I said, “I GOT THIS LAST KIDNEY FROM A CROTCHETY OLD MAN—JUST DON’T MESS WITH ME!”

The first time [transplant] I don’t think I ever thought like that. You know, it was mine. I never really thought about it. But I also wonder if it’s because-- They put me through hell; you’re not going to do it again. I think that might be part of it.

I remember one day I went into the clinic. And I had been on the one dose of cyclosporine forever. And it’s brutal. And the intern said to me, “why are you on this dose?” And I said, “every time you change my dose my creatinine goes out of whack.”

And he goes, “Oh, I think we’re going to do ‘this’.”
And I looked at him and I said to him: “you can talk till you’re blue in the face. I’m not taking any more or any less.” I said, “I want to see Dr. C--.” Anyway, he tells me to calm down, calm down.

It’s like don’t mess with me! I’m into this mess because I didn’t ask the right questions back then….

AM: and do you really think it’s from a crotchety old man or is that just something you say?

That’s just all I say—when I think back about me back in high school and junior high school and all that and I was a wallflower!….I had hearing aids and I had glasses. I was big, fat and ugly. I was deaf, dumb and blind. And even the school kids in grade 4 and 5—that’s what I went through. You know? So I was a very quiet, shy wallflower.

Getting your third kidney transplant from a crotchety old man is not the typical script for the blossoming of teenage wallflowers. In Kate’s narrative the kidney and its imagined donor become a metaphor for the virtues she has honed (assertiveness and courage, discipline and perseverance) in four decades of practicing a chronically unstable body and the counterweight of medical intervention. There are goods internal to this practice, Kate’s narrative implies, beyond the utilitarian goal of better health. “The exercise of the virtues is itself a crucial component of the good life for man,” MacIntyre states (172). Kate, the former wallflower, knows it is the virtues born of the long-haul that have caused her to flourish.

Why did it matter so much to recipients to be virtuous? Arguably, all persons with chronic illnesses must navigate the tears in their lives and the practices of the long-haul. However, transplant recipients are perhaps unique in their insistence on the spiritual nature of this quest, their metaphors of metamorphosis, their public liturgies of rebirth and their collective good works. “When you know you’re going to die and then you don’t” was astonishing. It brought recipients face to face with wonder. And that
sense of wonder was indelible, mysterious, forceful, whatever the denouement of their transplant story. It was, as so many expressed, simply good to be alive. “How did it feel?” I asked Maxine, “to compete in an event at the Transplant Games?”

It was the most…! I’ll tell you this—I didn’t know that my body could produce so much adrenalin. When I got up, for instance, on the diving platform, I was shaking! And my first reaction with that was “oh my God! This cannot be hypoglycaemia, can it? Not now!” Then I realized—it was adrenalin rush!

But the adrenalin rush! And all the way I just kept saying ‘swim as fast as you can!’ And ‘OH, I can’t believe, Maxine Creary!—YOU are doing this!’ And the feeling of absolute exhilaration. Such as I’ve never had before.

Recipients marvelled at their second chance. The Games were spiritual for Maxine precisely, she said, “Because I was given another chance at living. So spiritually that would mean that my spirit can continue to thrive when I’m alive…I will leave my mark, somehow, for the better, on some people.”

“It was like a door opening,” Sylvie remarked.

“Why do you think the transplant started that transformative process,” I asked Sylvie. “Or do you time it from then?”

“I think from then. Yeah. It might have even been before that. Just when I was waiting for transplant; absolutely when I was waiting.”

“Why then, do you think?”

“Well, because…like…uh…it was…” Sylvie’s voice stammered with choked back tears; she concluded on a sob: “It was my chance to do better. To be a better person. Do good for society. And the whole bit. You know?”

Brought face to face with wonder, with the realization of how good it was to be alive, a rejoining response rose up from many recipients: they were alive to be good. This is why it mattered so much to be virtuous.
Leroy

But I think if my family doctor had controlled the high blood pressure, I don’t think I would’ve lost my kidneys…. It’s a silent killer, blood pressure. There’s hardly any sense that it’s up. When I told the acupuncture doctor about my kidneys, he said that’s unusual. Unusual, he says, to have them go….

So anyway, that’s why I ended up in the hospital for 45 days. And I was on dialysis for two and a half years until I had the transplant.

So that was the pattern for me. But then, thank God, Lorraine came to my rescue [small chuckle] with that kidney, so….

AM: how did you guys get around to talking about it? Did the doctor talk to you first?

No, Lorraine brought that up. She didn’t bring it up to me, she told her mother. And so, my wife talked to me one day. She says, “You know Lorraine wants to give you a kidney.” And I said, “No, she never mentioned it to me.” She said, “Yes, Lorraine wants to give you a kidney. She wants to know how you feel about it.”

So when she came home from work, I asked her. I says, “Do you want to give me a kidney?” And she said, “Yeah. How do we go about it?”

And I said, “All I got to do is mention it at the hospital and they take care of it.” Cause that’s where it all starts….

AM: do you remember what you said to her or what she said to you?

Ummm…No. No, just normal. Just said, “I’ll mention this down at the hospital and they’ll take care of all the paperwork and appointments and all that”….

AM: did it feel special to have your daughter donate?

Oh, God! Yes! Yes. That’s for sure. For sure.

AM: what was the special part of it?

Well, I don’t know. I guess the fact that it was from her. And…I knew I’d be better off with hers than a cadaveric kidney. You know. My chances would be better. That was one good thing—the other thing, you know.

AM: the other thing?

Great. Everything great—I appreciate it. She knows that, too.
Lorraine, Leroy and his wife lived in a sunny suburban house, spotlessly tidy, amply stocked with photos and mementoes of his two grandchildren, his extended family and his Cape Breton roots. Downstairs in his rec room he took the time to show me a video of the sites and sounds of Cape Breton, especially his beloved down-east fiddle music. Upstairs in the kitchen we sat over tea and he told me in his gentle drawl and unpretentious style the story of his transplant.

Leroy married his childhood sweetheart at a young age and left Cape Breton for Ontario. They raised two children while he worked steadily, twenty years for Goodyear until they’d closed the plant, and another thirteen years with an electrical plating plant. “They were good to me,” Leroy said of his long-term workmates and employers. “And I was strong. I worked lots of hours, lots of work. No problems.” At sixty years of age, headaches, fatigue and irritability beset him, sure (but misdiagnosed) signs of high blood pressure. Rapid renal failure followed. He began hemodialysis, adjusted his diet, his days, his pace and his freedom. After two and a half years on dialysis, the transplant goes forward with Lorraine’s donated kidney.

Leroy was sixty-five when I interviewed him. There was no sense that he was in it “for the long-haul.” Both his illness and his transplant were fait accompli. “Like they say—all the books I’m reading—they say it’s not a cure. Ah, I say: it’s a cure. It’s a cure. You have to take medication, but that’s nothing.” There had been pain in the days following the operation. When the nurse insisted he had to get up, Leroy related: “Well, I thought I was going to die right on the spot. The pain! And you figure everything’s going to fall out of ya, eh? That’s the feeling you have.” But even in the immediate post-operative phase, “I knew I was going to get over it. It was only a matter of time.”
All that was required post-transplant was to be a little more conscious of infection, a little more careful about protocols for hand-washing, proper rest and diet.

Nor did Leroy find religious meaning or a deepening sense of spirituality in the occasion of his transplant. “I wanted to talk to you a little bit about your religious life,” I suggested. “Not much there!” Leroy replied. He was raised Catholic, he told me, had gone to church when he was younger and attended even in Ontario. “But now, since the scandal with the priests…turns me off, eh? You go to church and it’s somebody up there preaching to ya and he’s no better than yourself.”

Nor did Leroy feel that the transplant had strengthened his relationship with Lorraine, shifted his circle of friends or altered his sense of self.

“Do you think it changed Lorraine and you? Do you think you’re closer? Because I read all kinds of things like that and I wonder…”

“I don’t know,” Leroy said hesitantly. “Ah, Lorraine and I” he said, a bit resigned, “we’re always kind of a little bit struggling with one another anyway. For some reason.”

I burst out laughing at his candour.

“She’s kind of a little…uh…ah, we get along OK. Well—she wouldn’t have gave me a kidney, put it that way.”

Leroy kept in touch with his workmates, maintained his summer visits to Cape Breton, continued to play his fiddle with family and friends at house-parties and get-togethers. “I didn’t,” he replied, when I asked if he’d joined any transplant organizations. “I didn’t for the simple reason I’m not the outgoing type. I’m not. I don’t know what it
is. I hold back too much. Lorraine—she’s involved in the Dragonboat thing and things like that. She got involved in it.”

Leroy’s transplant did not transform his faith, his character or his life; “I got my life back,” he said to me. This is not to say that he was not extremely grateful.

Oh, ho, ho! Man! When I think back! Ah, geez! When I think back. I’ve got a lot to be thankful for, I’ll tell you that. Ah, believe me, I’ve got a lot to be thankful for. That’s for sure. If I get a little upset that’s when I stop and think: “You smarten up! Smarten up!”

And it does not mean he has no religious faith. “It’s a funny thing though. If you’re sick or if you’re down and out, you’ll always think of God. There’s no doubt about it.” And you? I asked. “Oh God! I was down on my knees too! Oh yeah, you pray, don’t worry.” Nor does the consistency of Leroy’s narrative imply a less ethical perspective, a less virtuous self. It only suggests that his moral compass and his moral community were not shifted by the events of his illness and transplant.

Leroy’s story makes an important point. Transformative religious experience is not inherent to transplant. It is pronounced in some narratives of organ transplant; it orchestrates a moral reorientation and spills into the social commitments of some recipients. My research solicited a disproportionate number of these people because it explicitly sought to talk to organ transplant recipients about religion. It is telling that Leroy did not elect to participate in the study on the basis of a poster he’d read or through affiliates in transplant organizations. I paddled with Lorraine on the Dragonboat Team and through her met her father.

Nevertheless, the fact that ‘wondrous’ transplants are select does not negate what can be learned from looking at organ transplant and religious experience. Attending to the wondrous (both the strange and the awesome) in the accounts of organ recipients
challenges the predominantly “principle-oriented” approach in both ethical and ethnographical accounts of organ transplant. It illuminates the dominance of health in our common cultural assessments of virtue and suggests that assertions of religious experience and inculcations of spirituality may encode alternate moral visions and a distinct moral community. Allowing for the validity of these responses to organ transplant may be important to assessing transplant “success” and recipient care. Finally, attending to the wondrous in the accounts of organ transplant recipients reminds us that religious experience is as much a part of contemporary religious life as it was in James’ day, one hundred years ago. The language, the setting and the religious exemplars may have shifted, but religious experience remains important to the formation, narration (and revision) of who we are and where we stand.

James’ understanding of the moral and psychic validity of religious experience was prescient. However, “the feelings, acts, and experiences of individual men [and women] in their solitude” (James 1902, 31) can only be a starting place for the study of religion. Orderlies and surgeons, religious traditions and dragonboat teams, siblings, spouses and crotchety old men are interwoven with the religious experience and the fruits of that experience. Even Kate’s solitary encounter with the mysterious visitor to the ICU connects to a wider religious and social world; Gillian’s supplications are a necessary part of Kate’s tale.

The hospital was Catholic, which I’m not, but that doesn’t matter. I still have in my cupboard a little novena that one of the nurses gave us because they did the surgery and we still didn’t know if Kate was going to wake up and she was too sick for dialysis.

So we started doing this novena (you were supposed to do it every hour, there was also one you did at the same time every day for so many days.) My husband, who’s not religious, was doing this in the car with me and Daria. We would pray these novenas together.
Well, whether it helped or not we don’t know because the doctor came to us on this particular day and said, “It’s out of our hands. It’s between her and the God upstairs.”

And we sat outside in the lot at [the hospital]. I remember crying and talking to God and saying, “You cannot take our sister. You took our mother and you cannot take our sister.” I remember sitting there with my sisters and doing this out loud. And anyways, the very next day! [Kate recovered.]

We don’t ever really stand in solitude. Individual men and women are hopelessly intertwined, even in the most powerful moments of personal religious experience. It is to the collective stories of sacred organs and the shared rituals of transplant that I now turn.

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1 Sharp (2006) is primarily addressing the “other-worldly” in the narratives of donor families. She conceives of them as “mystical denouement of sorts…one of many ways to make sense of a sudden death and tragic loss” (154). In recipient narratives she sees a correlate in tales of recipients incorporating donor traits—equally ‘ghostly’ and likewise deployed to “make sense” of the newly hybrid self. Clearly, this chapter concurs that such stories are about identity, but I am working with significantly different concepts of self and identity so that Sharp’s cognitive understanding of “making sense” has little relevance to the moral understanding of “making sense” I am developing.

2 Charles Taylor is also identified on Rorty’s list. It is not merely the construction of individual narratives that concerns Ricoeur, but the ways that construction interacts “with the text-worlds of literature, myth, and religion” (Wallace, 1995). “Taylor adds “neo-Neitzschean theories” to this categorization of “cramped” moral thinking and many of the theorists cited in this section do likewise, although Nietzsche is always treated cautiously, his ability to see past the limitations of obligatory action regularly noted.

3 Frank (1997) claims that even where “sociologists have taken the moral tasks of illness seriously…this work remains marginalized within medical sociology, just as writing by physicians that underscores the moral dimension of being ill is marginalized within medicine” (132).

4 The product of medicocentricism, Kleinman (1999) notes, is frequently the kind of reductionist data considered to be especially relevant to policy makers.

5 Rights vary for living and cadaveric donors, but include such issues as the right to be free from coercion, the right to be fully informed, the right to medical counsel separate from the recipient – and presumably the right to donate (although organ donation advocates sometimes lean towards writing this as a responsibility: “Sign your organ donor card. Lives depend on you”). Increasingly ‘rights’ to donor family ‘aftercare’ and donor commemoration is underscored by many procurement agencies (see Sharp 2006, 143-146). Recipient responsibilities are less formally articulated, but are structurally embedded in the evaluation of recipient candidacy and in the insistence on medical compliance. Recipients frequently have the responsibility of being medically insured to receive a transplant or, in Canada, to cover drug expenses. Even more ubiquitous has been the attention to ethical quandaries: brain-death dilemmas (and non-heart beating donors) have been extensively covered, as has the debate between required request and presumed consent. James Childress (1999, 2001) is the ethicist who has most systematically explored issues of organ allocation. The ethical dilemma of letting some die while saving others underscores not only organ allocation, but also the discourse of scarcity and its more radical resolution in organ markets, which raises ethical dilemmas on a global scale.

8 Despite the helpfulness of Frank’s (1997) general argument, I find his particular account of the “potential consciousness” of illness to be too linear, too convinced of the superiority of one kind of expansion.
In a Kantian frame we might want to talk about ‘reflection’, ‘choice’, ‘reason’, ‘will’ – but if we want to examine morality outside of a Kantian frame, outside the possibility of Platonic ideals and rational Habermasian discourses, the impetus to ‘change course’ in the narration of a live or ‘change hats’ in the identity of a self is inherently more problematic and philosophers are ambiguous. See Rorty (1989) when he declares we have to work with the “final vocabulary” we have “while keeping our ears open for hints about how it might be expanded or revised” (197). Of course, such a statement begs the question of how we would recognize a hint in a vocabulary foreign to our ears. Taylor suggests practical reasoning between moral alternatives hinges on our having “lived a transition which we understand as error-reducing and hence as epistemic gain” (1989, 72). But what prompts the transition goes unexplained. Ricoeur (1992) is emphatic that the self can only move beyond the identities of sameness, and even of the self, when confronted with something radically other “whose face appearing to me cannot be included within the sphere of my own representations” (335). His position is closest to the arguments I am making here.

It is central to MacIntyre’s argument that without a narrative unity, a guiding telos, or communal good, such characters offer only a derivative (and divisive) pretence of virtue. Nevertheless they are held up as modern versions of virtue.

Bitter stories of the double burden of being a minor in a biomedical model that discounts the embodied knowledge even of adults were endemic to the accounts of those who had been chronically ill since a young age.

The extensive social commitments of transplant recipients have been noted by Sharp (2001, 1995) in connection with the ‘tyranny of the gift’. Equally prevalent, I found, was the ‘guilt’ long term patients feel at leaving the moral communities of medical staff and fellow patients. For a discussion of this guilt and the limits of the ‘tyranny of the gift’ analysis, see Chapter 2.

Personal communication, Dr. Michael Hutchinson, Intersections of Life and Death Conference, May 2007

Williams (1993) makes a similar point when he counsels that general prescriptions provided by professionals for people with chronic illness “may be resisted, forgotten or ignored…because they rest upon a set of presumptions about the meaning and significance of illness that are not wholly shared by the patient”.

If the Manager qualifies as one of the most instructive and pervasive moral characters of modernity, the other, argues Alasdair MacIntyre (1981), is the Consuming Aesthete, “committed to the aesthetic pursuit of his own enjoyment” (23-24). MacIntyre has in mind a broad satisfaction of individual attitudes and preferences, but one component of the aesthete would seem to be the completion of the self through the pursuit of corporeal perfection.

It is ironic that ‘athletic games’ are so much the centre of transplant constructions of moral worth. I suspect that the Games represent both parody, and hence an oppositional discourse to the hegemonic force of the healthy ethical self, and a sincere attempt to include themselves in this dominant moral discourse.

This truncates MacIntyre’s definition of virtues. In his schema it is imperative that “the overriding conception of the telos of a whole human life, conceived as a unity” (188) order and complete the notion of virtues. It would be stretching the experience of illness and transplant too far, or at least stretching my ethnographic data too far, to claim that it provided the unifying frame for recipient lives. What clearly emerged from the ethnography, however, was an identifiable sense of the ‘practice’ of chronic illness and high-tech medicine and the virtues required to participate in the same.
Chapter 4: Rites of Decorum, Invented Ritual & Ceremonies of Citizenship

It was ’72, I guess. Yeah, I think it was. I started dialysis in something like August then I got the transplant the April of ’73. And I have a, I could probably [inaudible], a name for my kidney: it’s KB, and that’s for Kidney Bean.

Oh! And this! I almost forgot to tell you. I got – this is the gold kidney that I got. [She is lifting the necklace she wears so that I can see the pendant.]

My family gave me it on my 25th anniversary. So it’s always there. You know, my gold kidney here [she indicates her necklace] and here [she indicates a spot below her midriff where the transplanted kidney sits].

AM: They had to have it made, I’m sure.

Well, my brother’s in the jewellery business, so that helped…

AM: What did you feel like when you opened that up?

It was very special and some people say I should get it engraved, but I just like it plain. I know what it’s for and stuff, and I just like it plain. It’s very special. I had good family support, um, between my parents, the brothers, you know.

At nine years of age puzzling symptoms (that Sally herself cannot quite remember, “maybe urinary tract infections and stuff”) prompted a referral to the Hospital for Sick Children. Once there tests and examinations revealed several things. That Sally’s ureter, conveying urine from the kidneys to the bladder, was crooked. That Sally had been born with only one functioning kidney, the second having formed but not grown. And that the blockage of urine caused by the crooked ureter had irreparably damaged her one functioning kidney. Sally was told about the crooked ureter to prepare her for the surgery she would immediately undergo to correct it. But her parents declined to tell her what the doctors had told them: that in time the damage to her only kidney would culminate in renal failure, dialysis and possibly transplant.
Towards the end of high school, Sally – a competitive teenage athlete in several sports – was sidelined by the decreasing function of her kidney. At seventeen the knowledge her parents had guarded for years came very much as a shock. “I remember having to have some surgeon explain it to me two or three times. It just didn’t set in that I was going to have to be attached to a machine. And I remember he’d explain it once and I would have to have him explain again, because it just, I just didn’t believe it.” She began hemodialysis treatments at the Hospital for Sick Children, a downtown Toronto hospital some distance from the western suburbs where she lived. As a young and otherwise very healthy dialysis patient, kidney transplant was much the preferred treatment. Eight months after she began dialysis, Sally received the call that a donated kidney was available and she underwent transplantation at the Hospital for Sick Children. Sally knows only that the donor was a small child, 3 or 4 years old, and she presumes that the donor was also a ward of the Hospital for Sick Children.

The transplant necessitated at least two months of recovery in hospital, much of it in isolation. Sally distinctly remembers the surgeon being exceedingly pleased with how the donated kidney was performing, but there was great difficulty controlling her blood pressure, there were episodes of rejection, and there were physical and emotional reactions to the high doses of immunosuppressants supporting the transplant and checking the rejection. “I was going a little bit squirrely with all the drugs I was on”, Sally recounts, and she remembers lamenting her swollen ‘moon face’, both known side effects of immunosuppresants, particularly those of that era.

I remember writing a letter to my friend at school and saying – I forget the exact words, but something about warning them that I would maybe look different. ‘I’m gonna have just, you know, the round cheeks and stuff, the typical face.’ I think I even remember the line: ‘Even if Queen Elizabeth had to take prednisone, she would even have a moon
Some line like that is sticking in my mind! But I remember writing them, so I must have felt that I needed to get it out of me. To warn my friends, or something about me I wanted them to know.

The benefits of the transplant were indeed hidden in the early months following surgery. “I guess my mom in particular didn’t like seeing me that way and stuff,” Sally recalled. “And I think she even talked to the other doctor, like the medical doctor, saying ‘Can you take the kidney out?’” At this Sally laughs in astonishment, and explains: “That’s a parent, you know, looking out for their kid and stuff.” I ask what it was that most concerned her mother. “Hmmm”, Sally pondered, “it’s been so long, so far back for me. I guess – I guess you’re just not yourself. [Pauses.] And that did, that did certainly settle down. And fortunately they didn’t take the kidney out!”

‘Fortunately’ because both Sally’s health and the health of the donated kidney have proved extraordinarily durable. I interviewed Sally in the winter of 2004. It would be impossible to guess that she was almost fifty. Tall, slim and exceedingly fit, she exudes good health. Bright-eyed, loquacious and energetic, only the traces of grey in her fair curly hair hint at her age. The donated organ has fuelled a very active life. Sally completed high school after her transplant, received further training as an X-ray technician and subsequently as a medical transcriptionist, her current occupation. But her professional life is clearly secondary to her passion for athletics. She resumed competitive paddling some ten years after her transplant, emerging as one of Canada’s elite dragonboaters, competing nationally and internationally. She also discovered transplant athletics, in particular the International Transplant Games, and has been instrumental in generating recipient involvement through the Canadian Transplant Association, which she helped found. She has managed, motivated and mothered ‘Team
Transplant’, the dragon-boat team made up of transplant-related participants, since she conceived it a decade ago. Combining her love of paddling, her hopes for recipient health and her commitment to organ donor awareness, Team Transplant is perhaps the endeavour closest to her heart.

We spoke at Sally’s home, a small bungalow in a suburban city just a few blocks from the home she grew up in. Sally was single, but lived with and cared for her aging and ailing mother. Vera sat on the periphery of our conversation and at Sally’s urging would occasionally, with difficulty, add a few words. The three of us were joined by pictures, newspaper clippings, letters, cards, videos and mementos that documented the transplant people, moments and events that Sally felt were important. “It’s got to be boppin’ around here somewhere”, was an oft repeated refrain as Sally would dig through the comfortable clutter that marked her home. The transplant and the ever-expanding ripples of affect and association it has produced seemed always close at hand. So close at hand that it was only several days after the interview that I fully recognized: Sally’s transplant took place over thirty years ago.

But it has remained as visible and present in Sally’s life as the glinting gold necklace that she always wears. Indeed, the necklace resuscitates and amplifies the transplant; it is not mere reminiscence. The gold kidney dangling from its chain is intended to symbolize the ‘golden’ kidney that has allowed Sally to live fully – and long enough to reach her 25th anniversary. However, as Victor Turner (1974, 1967) made indelibly clear, there is nothing static or univocal about symbols. The necklace is not only about kidneys and glowing, golden health, but also about gift givers, both the long-ago donor and the on-going circle of family. Symbols are the “molecules of ritual”
(Turner as quoted in Grimes 1995, 156) and ritually deployed (as in this anniversary gift) they have the capacity to enliven memory, to stir imagination and to harness both to knowledge and action. All this would be a lot to claim for one ritual transaction. But Sally, tactile and kinaesthetic, made clear to me how constant and important is the ritual elaboration of her transplant, and how those rituals in turn both perpetuate and elevate her transplant.

AM: When you opened your necklace, you said it was like you were celebrating the anniversary of your transplant. Do you do that every year?

I do, I do. I’m sure the rest, all of us, do on our anniversary. I call it an anniversary, some people call it a birthday. Oh, and especially when you have a major one. Sort of every 5 year thing, the 5th or the 15th—fortunately I can rhyme off all of these to you! I can’t believe myself how time has gone by and I’m doing as well as I’ve done.

AM: what did you do on the first one? Can you remember the first anniversary?

Oh, if I’m not mistaken, well, I think my brother sent me roses. So that’s never happened again!! (We laugh heartily.) But I think after the first one, I think I might’ve got, what I did on what special -- I remember one anniversary I did go back to Sick Kids and sat where I always sat waiting for my dad, in front of that thing. And just going back to Sick Kids on my anniversary and looking up at the windows facing University Avenue, that place where the ICU was, just looking up there. Just all the little things that I do. In the narrative and ritual threads that Sally has woven from her transplant, her father’s presence looms large. A tragic accident in the cottage garage killed Sally’s father six years after her transplant, when Sally was just in her early twenties. It was a tremendous loss. What she has lost -- a stalwart family man, his gentle love and unflagging support -- she often condenses into her memories of the liminal days of dialysis and transplant. Memories of his regular attendance despite his strong aversion to hospitals: “dad’s not one for hospitals, you know, and seeing blood and stuff”. Memories of his awkward bedside manner: “dad used to put his hat on the bed and I guess mom’d
say, ‘no, you can’t have your hat on the bed, or he would sit on the bed and mom would say, ‘no, no sitting on the bed’’’. Memories of his lunchtime visits, moments stolen from work to bring a box of Kentucky Fried Chicken to the hospital: “I remember sitting out in the front of Sick Kids in that driveway thing. I think about how I used to sit there waiting for him and behind me were the stained glass windows of Jesus. And I can always remember that.”

“All the little things I do” came back to Sally as she retold the memories of the space that had contained her transplant experience and the people that had populated it.

With a small laugh she continued:

Actually, more things on my anniversary than I realized. When I was in ICU they said ‘OK, Sally, you can eat whatever you want’ (this was after a bit of time in the ICU, and things had settled down). For some reason what popped out of mouth was ‘lamb chops, mashed potato and creamed corn’. I always liked that combination. So now on my anniversary that’s my anniversary meal. I’ll have lamp chop and mashed potatoes and creamed corn… So I’ve been doing that for a while. And, um…trying to think what else…Well, I always have a little bottle of champagne. Have to have champagne.

And one of my anniversaries – and I actually have that on video too – is out at the cottage, which is a very special place for me too [in addition to Sick Kids]. It must have been one of my major anniversaries… must have been for my 25th anniversary I had a party at the cottage. Now that would’ve been in April, so a little bit cool, but a lot of my transplant buddies [attended]… A girl I knew from the Canoe Club did cake making on the side and so I had her make [the cake] for me. Yeah, it was a good cake. I liked the jellybeans. That was—it was honestly her idea. Jellybeans look like little kidneys…

It was out at the cottage, which I love… And I guess that’s where I wanted to spend my 25th anniversary, with my transplant buddies, they’ve been a big part of it. That’s where I had my 25th one. [Her ‘transplant buddies’ are the people she has met and befriended at Sick Kids, through transplant athletics, and from the CTA.]

So every 5th anniversary, I get – I didn’t do a big thing for my 30th. Oh, I shouldn’t say that! No I did do—that was tied into that walk [60km fundraising walk for breast cancer] that L. [fellow transplant recipient] and I did. That was my 30th year last year. Even though my anniversary was in April and the walk was in September, I sort of had that in mind: to do it in my 30th year of my transplant…

AM: just kind of marking that ‘I was healthy enough to do a walk like this?’
Yeah. Yeah. And in memory of my donor, you know. And that. So even though it wasn’t in April, it was still that year. So I did that walk sort of with that in mind.

AM: Do you think about the donor on the anniversary?

Oh, for sure. For sure, and the family. Yeah, for sure. Especially on the anniversary. Maybe not, you know, so much in between. But it still pops in our heads, for sure. But especially on the anniversary, and especially what that family’s going through. There’s always two sides to the coin. Where it’s a happy anniversary for me, but then a hard anniversary for the family— their child would’ve been that many years old and stuff.

I did try finding my donor. Didn’t pursue it too much. But I did go, I did go to the big Toronto library down there on Yonge Street and went to the obituaries for right around that time. April 14th. I thought I saw one that sort of did…but anyways, I didn’t really know… Yeah, didn’t pursue it to any sort of great degree… I think that was for my tenth; that was the thing for my tenth anniversary.

I never did push through it to that great of a degree. It’s just in my heart, and, uh, yeah. [Pause.] It’s different in the States. It seems you’re able in the States to put flowers on the grave and stuff. You know, I would’ve appreciated that. Cause, even my own dad’s spot—I don’t go up there as much as I used to, but you know, I go up there. Not everybody’s one for going back to cemeteries and stuff, but I bet I would do that. Yeah. I never thought about it, but I think I would. Well, I know I would. If I knew my donor and where the little one was buried, I would’ve taken flowers and probably on my anniversary. That would’ve been an anniversary thing. Yeah. But I guess I’ll [voice trails off]

You definitely think of the donor and the family, especially on the anniversary. And I named--I got a name for the kidney. As I said, KB – the KB is for Kidney Bean. So ’73 was the year for KB.

The ethnography of organ transplant seldom fails to mention the rituals of transplant, although they rarely, if ever, call them that. Donor memorial services have received concentrated attention (Sharp 2001), as has the ritual of thanking the donor family in a letter (Lock 2002, 320-328; Sharp 2001, 123, 127; Sharp 1995, 376). The propensity of recipients to name their organ, mark the date of their transplant or participate in sporting events is mentioned, but not elaborated (Sharp 1995, 372; 2001, 124; Hogle 1999, 191). Post-transplant actions are considered independently and
selectively, often to exemplify a psychological (Lock 2002, 327-328, Sharp 1995) or political (Sharp 2001) analysis.

What, however, if the myriad embodied performances, stylized gestures and symbolic displays that trail in the wake of transplant were considered in tandem, as like objects, as a category? That is precisely the challenge of this chapter. Despite the variation between solitary vigils to reference libraries, cake cutting with friends, and global gatherings of transplanted athletes there is usefulness (and an inherently satisfying fit) in considering them collectively, as rituals—or more precisely “ritualizing”, a term ritual scholars have used to denote the activity of deliberately cultivating or inventing rites (Grimes 2000, 29) and to emphasize the practices of distinction and juxtaposition that build ritual knowledge (Bell, 1992). Not surprisingly it is to ritual studies, a somewhat fuzzy field with roots extending into religious studies, performance theory and anthropology, that I look for guidance. This is not a turn that organ transplant scholarship generally takes and ritual studies affords new insights and challenges some established wisdom about the post-surgical activities of transplant collectives.

If ritual theory is not the handmaiden of transplant scholarship, neither is organ transplant a well-travelled path in ritual studies territory. This chapter’s close examination of transplant’s blatantly invented rituals, rituals both private and public, rituals inextricably linked to forces of technology and only tangentially linked to traditions of religion also contributes to the theorizing of contemporary ritual.

In recent decades, scholars have convincingly overturned earlier stereotypes about rituals: that rites routinely enact myths, inscribe moral principles, and are bastions of social conservatism (see fuller discussion in Grimes, 1995, 60-61; 1996, Introduction).
Newer understandings of ritual as a generative source of culture, structure and transition are deeply indebted to the wide-ranging work of Victor Turner (see for example 1974, 1967). Particularly influential has been Turner’s notion of social drama as underlying both narrative and ritual. In Turner’s schema, social dramas take a four-stage form: breach between social elements, crisis, adjustment/redress and, finally, reintegration of the group/person/element into social structure or recognition that the initial breach was irreparable.

There is little doubt that organ failure and the transplanting of solid human organs can be considered a dramatic breach. Sally’s narrative evidences the myriad ways that kidney failure, dialysis and transplant “breached” the trajectories of her body, ‘self’ and social world: the slow erosion of kidney function, the shock of being machine-dependent, the months of commuting to Toronto for treatment; the disrupted body of a budding athlete, the disrupted education of a high school senior, and the disrupted appearance of a peer-conscious teen; the surgical invasion into the body and the turbulent psychological and physiological response to transplanted tissue and chemical ministrations; the invasion into consciousness of a foreign body part, a dead toddler and its grieving yet generous parents. The physical, emotional and social rupture recipients experience is well documented (in the social scientific literature see for example Sharp 1995, in the extensive psychological literature see for example Craven 1992; DiMartini 2000; Stotland 2002). But transplant scholars have also emphasized the ways organ transplant troubles the body political, the body social and the faithful body. Transplant rewrites traditional definitions of death (Lock 2002), alters norms about the use and misuse of dead bodies (Hogle 1999), widens divides between the disposable bodies of the poor and
the precious bodies of the wealthy (Scheper-Hughes 2000), and questions Christian notions about the embodied soul and its posthumous resurrection (see Chapter 1). Clearly the breach posed by organ failure and organ replacement is substantial.

In Turner’s view, critical breach demands redress. Ritual action is a primary form of articulating the breach, bracketing it from other kinds of social action and creatively exploring novel adjustments and adaptive strategies. Turner’s well-known concept of “liminality” (a suspension, inversion or even violation of normal rules and roles facilitating either the revision or re-incorporation of such rules and roles) is endemic to this third redressive stage of social dramas. Borrowing at least this much of Turner’s theory, this chapter argues that transplant’s formal liturgies and ceremonies, and recipients’ persistent ritualizing (encompassing rituals of decorum, commemoration, naming and healing), can broadly be considered redress to the physical, psychological, social and spiritual breach of organ transplant.

I am less comfortable following Turner to the conclusion that ritual redress either resolves transplant tensions (leading to the reconfiguration of fractured social norms and the reintegration of recipients’ bodies, lives and selves) or, conversely, acknowledges the irreparability of the breach encountered. Turner’s schema is indebted to Van Gennep’s articulation of rites of passage, and ‘passage’ is not the metaphor that most effectively captures the on-going drama of transplant: for recipients, the perpetuity of rejection fears and immunosuppressant drug regimens; for donor kin, the organs of loved ones that continue to ‘live on’; for cultures, the ambiguity of “brain-dead” bodies (Lock 2002) and the ambivalence of “patchwork” men and women (Fox & Swazey, 1978, 1992). Just as Frank (1995) described illness narratives of “restitution” as inadequate for postmodern
medical treatments that offer reprieve but not cure, the ritual work of transplant recipients is on going and does not have a singular, tidy ending, positive or negative.

What, then, is such ritual work doing? There are transplant rituals that seek overt transformation, striving for social and spiritual renewal much as Durkheim (1965) described or seeking individual passage and status change such as Turner (1974) and Van Gennep (1960) theorized. There are transplant rituals that celebrate more subtle transformations, transformations of desire, expectation, and frames of reference, the kind of ritual magic that Driver (1991) elaborates. Scholars have also made clear the more prosaic work of rituals and there are transplant rituals that facilitate the subtle social interactions that encircle us (Goffman 1959, 1972). Neither rituals of transformation nor rituals of maintenance are apolitical; transplant rituals are frequently both strategies (Bell 1992) and moral projects (Driver 1991). This list may appear to overlook the obvious—transplant rituals and the work of increasing organ donation—but one of the most immediately apparent features of transplant rituals, one that many recipients, donors and professionals have pointed out to me with chagrin, is that “they are preaching to the converted”. The very fact that transplant rituals seem ill designed to engage potential organ donors suggests, as Bell (1992) suggests about ritualizing more generally, that organizers and participants habitually misrecognize the goal of transplant rituals.

Also key to Bell’s (1992) theory of ritual is her notion of the “ritual body”: a body invested with a ‘sense’ of ritual. This ‘sense’ extends to practical mastery of strategic schemes, generates social instinct for creating and maintaining contrasts, and provides a logic embodied in the physical movements of the body. The practice of ritual, Bell argues (1992), inculcates the “production of ritualized agents, persons who have an
instinctive knowledge of these schemes embedded in their bodies, in their sense of reality, and in their understanding of how to act in ways that both maintain and qualify the complex micro-relations of power” (100). Her theory is useful for considering the close knit between the practice of transplant rituals and the invocation of a transplant community.

It is clear that something like a “ritualized agent” is being produced in the ritual practices that surround organ transplant. The common claim is that recipients have an intuitive understanding of how to act. Consider Sally’s response when I asked if she celebrated each anniversary of her transplant: “I do. I’m sure the rest, all of us, do on our anniversary. I call it an anniversary, some people call it a birthday.” There is also a general perception that recipients have an awareness of the donor embedded in their bodies. Consider Sally’s assertion that the donor and their family “still pops in our heads, for sure…especially on the anniversary”. Most assuredly there are transplant recipients who do not celebrate their transplant anniversary, name their kidney or engage either donor or donor kin in their heads -- organ recipients do not think or act intuitively or instinctively. It is precisely participation in the rituals of transplant that ensure the kind of ritualized agent that can claim access to the social world of “transplant buddies” that Sally describes. Participation in the rituals of transplant engenders an intuitive ritual knowledge, shared sense of reality, and particular embodied understandings. It is by dint of acquiring transplant’s “ritual body” that one gains membership in the oft mentioned “transplant community”, not by dint of acquiring an organ.³

The ritual body (some) transplant recipients acquire and its correlate – the collection of ritualized agents that define the transplant community – is both a private and
a public phenomenon for the rituals of transplant blend, in complex and diverse ways, private lives and public spheres. A close examination of three transplant rituals follows. Each offers determined, yet distinct, redress to the significant breach posed by organ failure and a treatment modality that engenders still other social, spiritual and physiological ruptures. And each performs the intimate and private in conjunction with very public discourses: about morality, about transplant, about healthcare and about the nation.

**Rites of Decorum**

Camp Dorset is a dialysis vacation centre in the heart of Muskoka, Ontario’s “cottage country”. On the shores of a small northern lake a cluster of cottages, housekeeping suites and trailers surround two communal buildings – the camp’s recreation centre and the medical clinic where patients dialyse while attending camp. The camp is possible due to the long-distance support of Lions Clubs across Ontario and the hands-on dedication of the camp’s very committed husband and wife administrative team. Each week of the summer the camp hosts a participating Ontario hospital or pair of hospitals. In “their” week the hospital sends both patients and nursing staff to the camp, a retreat from the city and an escape, if not from dialysis, then from clinic routines. For one week each fall the camp opens its doors to both renal patients and kidney recipients; I conducted interviews at Camp Dorset during the fall ‘recipient’ week in 2004. One of those interviews was with Dale, who had attended Camp Dorset in previous years as a dialysis patient. This Thanksgiving, however, he was attending as a multiple organ recipient having undergone a kidney/pancreas transplant some 18 months prior.
I did my dialysis at [a hospital] in [a northern suburb of Toronto]... And I read all the material. Like they give you *all* these books on dialysis. [He gives a robust chuckle.] And there’s so much, when you go through it, as you know! You go through it all, you’re reading it, but how much do you digest? And the only -- there’s only this one word I really remembered and that was ‘camp’... Yeah, sure you got dialysis and you got medication and all this kind of stuff. But once I’d read ‘camp’; there’s a camp and it’s in Dorset. Well that’s beautiful, that’s home then.

Dale’s immediate affinity for Camp Dorset stemmed from the attachment he feels to his family’s cottage, also located in Muskoka, and from the many, many seasons he spent as a counsellor at Camp Huronda, a diabetes camp for kids. Dale was himself an insulin dependent diabetic for 23 years, from the age of twelve until his recent pancreas transplant. It was diabetes that led to the failure of his kidneys. As a child he was unaware of Camp Huronda. As a young adult he became passionate about the camp’s mission and residents. Gregarious and witty with a flair for performance, Dale developed a well-loved and oft deployed repertoire of skits, jokes, characters and songs while a camp counsellor.

New routines of pointed satire and poignant humour emerged at Camp Dorset, the pre-eminent being the regular rounds of Dr. Ben Dover (pronounced “bend over”). A white medical coat covering his stocky figure, a beanie cap complete with twirling propeller above his round face, eyes twinkling behind his wire rimmed glasses and medical bag of very odd accruements at his side, Dr. Ben Dover descends upon the dialysing patients and ministers to them in his own unique way. Quite simply, Dale was Dorset’s resident ritual clown: fully aware of the serious nature of being chronically ill and dependent on biomedicine, and fully able to play with that knowledge.5

You see this carefree kind of guy or everything like this, you know, wild – but like I said before, down to the core... I take my blood sugars everyday. And I take my blood pressure everyday, every morning. And I take my temperature every morning... And I tell my [transplant] team: ‘here are my results. These are my blood sugars.’ And ‘all
right [they say] why are you doing that?’ Well, I’m taking this very seriously. This is my life. I’m extremely cautious and I’m very knowledgeable about what’s going on.

Dale also took seriously the generosity of his donor and the ritual of thanking the donor’s family. Long before Dale received his transplant he was certain he would send a letter to the donor family.

After they told me, you know, there’s the option of transplantation… ‘If you pass all your tests, would you be interested’? Yes, yes. There was no thought, there was no doubt… And the letter option—yes. Definitely want to write to them. No matter what happens.

But constructing the letter was not as instantaneous. Discharged from hospital a mere seven days after the transplant of both pancreas and kidney, he nevertheless experienced months of extreme fatigue. “I was exhausted so much I couldn’t watch the Leafs’ playoffs!” exclaimed Dale, like many Torontonians an avid fan of the city’s professional hockey team. “I just wanted to rest up and go to bed. And I got up, and you know, not even watch the first [period] and go to sleep and then wake up and it’s the end of the game.” Throughout those tired early months Dale processed his thoughts about his new organs, his unknown donor and the juncture his life had reached, jotting his reflections on a sheet of paper in preparation for the one official act of connection allowed transplant recipients and organ donor families. Some six months after his transplant, sitting on the dock at his family cottage, relishing the calmness and the centeredness he felt there, Dale marshalled his thoughts into formal prose and wrote them out on carefully selected stationary.

The letter was not directly sent to the family of his donor. Protecting the anonymity of donor and recipient is paramount to transplant professionals, even though it is transplant professionals that encourage, coach and coordinate the writing of letters to
donor kin. Dale discovered the option of writing the donor family in the medical information manual given to potential transplant recipients. Briefly explaining the desirability of offering thanks, the information manual primarily stresses that no identifying information, such as location, occupation, name, age or other personal details, should be included. To ensure that no such information passes hands, a transplant professional (usually from the organ procurement organization) opens, reads and vets the letter before reaching into the database for the proper address and sending it on. “It’s not pleasant,” one organ procurement professional told me, referring to the process of taking a bottle of white out and dabbing through someone’s handiwork.

One year after its completion, at a kitchen table in a spartan cottage at Camp Dorset with the brilliant colours and sunshine of a northern autumn pouring through the picture window beside us, Dale read me the letter he wrote. “OK,” he began, steadying his voice. “I’m very proud of this letter.”

Dedicated to my heroes. And I thank you.

I’ve travelled to a very special location which holds a beloved place in my heart so I could try to properly express to you my enduring gratitude for my treasured kidney and pancreas. As I look over my calendar, I discover that it’s been little over six months since our transplant operation. I thought that maybe this time frame would allow us both to heal from the magnitude of late March 2002. Although I know only too well what the loss of a close family member means to all of us who loved them so.

Let me begin by saying that I feel great. The transplant went extremely well and I was released from the hospital in just 7 days. My recovery was slow and steady and has progressed at a glowingly phenomenal rate. My blood results which monitor the acceptance of my new organs are excellent. I take numerous anti-rejection pills daily along with other medications to assist in my progress.

The fact that these two gifts of life have quickly become my best friends makes me promise to all involved that I will do my best to prevent any complications from happening.
I have been tremendously supported by a team of fabulous physicians and nurses. I am also blessed with unconditional love, kindness and understanding of my family and friends. After so many years of battling diabetes and a few years on kidney dialysis, I can honestly and happily report to you that the thought of taking no more insulin needles and being off the dialysis machine brings a warmth of incredible delight and relief to my soul.

We read the newspapers and watch the television every day and we are saturated with people who bring much evil and danger into our society. Then there is the story of my dear donor and their family. How refreshing it is to be associated with such giving and caring individuals who thought of others at a most trying time of their lives.

Your generosity may not have made any headlines, but let me tell you that it was a front page celebration in my circle of life. Please take with you a peaceful salvation in knowing that your loved one’s organs have helped to provide good persons with a second chance.

It is now time to focus on health, love and life. I look forward to the journey.

I truly hope that these words provide you with some delicate comfort. I also wish that you see in my revelations the beautiful actions of your life saving gesture.

I cannot tell you how many times I’ve tried to start this letter to you. It was the most difficult, yet the most meaningful letter I have ever -- and probably will ever -- write to anyone. And I thank you.

Passionately written with continuous tears of joy, love and remembrance,

One lucky and fortunate multiple transplant recipient.

Dale’s voice is broken as he nears the end of the letter, catching and crumbling. I am snuffling and sniffing, reaching for the Kleenex box. “It gets me,” Dale states. “It still gets me. It’ll always get me. I hope it does.”

Writing a letter to the family of the deceased organ donor is a central rite of organ transplant. It is central to transplant professionals who actively invite recipients’ participation, carefully shape the ritual etiquette (elaborating rules, providing suggestions) and devote considerable time and resources to orchestrating the rite. The
staff member at Ontario’s procurement organization related that TGLN continues to white out identifying remarks even for people who have been in contact for years. Officials at both Ontario’s and Quebec’s organ procurement agencies told me that this rite was central to donor families who are very active in seeking (generic) information about and (anonymous) contact with the recipient of their loved one’s organs. It is central to organ recipients, not because all or even most participate in this ritual, but because all of them are aware of this ritual possibility and feel its interpellation. And, finally, it is a central rite for scholars of organ transplant, particularly anthropologists, who routinely ask recipients about the letter to the donor family (see especially Lock 2002, 320-328).

In the scholarly assessment of letters to donor families the predominant issue is an assessment of the impact and desirability of maintaining anonymity (see Lock 2002, Sharp 2001) rather than an evaluation of the rite’s motivation, construction or function. The recipient letter is most often described as a letter of “thanks”. It is presumed that a feeling of gratitude motivates recipients to participate in this ritual. But such an analysis is thin; it describes too little and leaves too many questions. My ethnographic accounts demonstrate extremely grateful recipients who decline to write a letter to the donor family (see also Lock 2002, 320-328). Dale’s letter articulates much more than thanks. And neither thanks nor gratitude explains the enthusiasm of transplant professionals and donor families for this rite.

My contention is that the letter recipients are invited to send to organ donor families can be fruitfully explored as an interaction ritual: a conventionalized performance, based on the well established formalities of thank-you letters and letters of
condolence, designed to assert and protect particular “faces” for recipients, donors and transplant professionals. This argument draws heavily on the work of Erving Goffman (1959, 1972) who proposed that the customary behaviours, etiquettes and pleasantries between socialized persons are best understood as a sort of ritual, “interaction ritual” in his terminology. According to Goffman, the primary function of interaction ritual was to establish, maintain, present and repair the ‘face’ – the self-image or persona -- of participants. “One’s face, then, is a sacred thing and the expressive order required to sustain it is therefore a ritual one”, he wrote (1972, 19).

Yet Goffman’s concern was not with “the individual and his psychology, but rather the syntactical relations among the acts of different persons mutually present to one another” (1972, 2). He described the “face work” of various conventionalized behaviours as being tacitly cooperative, participants being equally concerned with protecting one’s own face and “saving” the face of others. His claims are sociological, not psychological, and this is reflected in the language of his successors who term their research “microsociology” (Collins, 2004).

In attending to the performances, gestures and symbols that mark the rituals of everyday encounters -- the tipping of a hat, the routine patterns of greetings and farewells, the rules of conduct at meals -- Goffman was most concerned with those interactions that take place “face-to-face”, in the presence and witness of others. However, he did acknowledge that the performance of self, the rituals of deference and demeanour, also took place in “mediated contact with other participants” (1972, 5) and that the “lines” that participants enjoined to establish certain aspects of their “face” could be gleaned from “such things as written statements and work records” (1972, 33).
Although it lacks the immediacy of the face-to-face performances that Goffman most routinely explored (hardly possible given the anonymity of organ exchange), the letter recipients write (or do not write) to their donor family is an excellent example of using “mediated contact” in the ritual negotiation of social place and face.

“Face work,” writes Goffman, “serves to counteract ‘incidents’ – that is, events whose effective symbolic implications threaten face” (1972, 12). The scholarly examination of organ transplant has solidly demonstrated that this technology, particularly when it involves donors declared brain-dead, is rife with threatening symbolic implications for all of the parties involved, symbolic implications that have direct ramifications to the ‘faces’ of recipients, donor kin and transplant professionals. Donor kin are recorded as frequently having misgivings about their acquiescence to donation. They fear their permission to harvest organs from the deceased might be interpreted as callous, designating them as unattached to the bodies and memories of their loved ones (see Sharp 2001, 126-128). Transplant professionals (doctors, nurses and procurement officials) worry in ethnographic accounts that they might be transgressing their professional oath to do no harm, particularly as the professional community cannot wholly align itself with the designation of brain death (Lock 2002; Sharp 2001, 121-122). Failure to uphold that oath would mean that the ‘face’ of a caring, committed health care worker would be unavailable to them. Recipients have two kinds of face reservations. They worry that they might be seen as greedy or insensitive, snatching organs from the dead, taking an organ for themselves while another human languishes or dies, or even surreptitiously responsible for the death of the donor in their desire for an organ. Secondly, they worry that their ‘face’ might be altered by the ingestion of an organ that
carries some other kind of persona than the one they would most like to present (Sharp 1995, Lock 2002, 320). As Dale raced to the transplant centre after receiving the call that organs were available, one of the thoughts that plagued him was, “Where’s this organ coming from? You’re thinking is it some nice person? Or is it, you know, some psycho-killer!”

It is important to stress that donor families, transplant professionals and recipients do not necessarily have to believe they are callous, irresponsible, greedy or insensitive to be induced to undertake the ritual correction of ‘face-work’. They simply need to be aware that the symbolic implications of donating, accepting or facilitating transplanted organs might paint them as such. To seek out face-saving practices, Goffman writes, the participant must be “properly alive to symbolically conveyed judgements” (1972, 13).

The advantage of considering the letter recipients write to donor kin as an instance of face-work, an action designed to counteract the symbolic implications of transplant, an action seeking to alleviate participants who might be “out of face”, “in wrong face” or “shame faced” (Goffman, 1972, 8), is that it goes considerably further in explaining the commitment of all three parties to this ritual interaction. Describing it as a letter of thanks from grateful recipients can only offer a singular motivation for the party most ambivalent about this rite (nor does it offer any insight into their ambivalence).

For Dale, a number of concerns about his ‘face’ were resolved by the writing of his letter and by an answering letter written by donor family. Dale had just received that treasured letter when we conducted our interview. He asserts in his own letter, in the details and in the act of writing it, a persona of compassion and caring, resolutely communicating his disassociation with possible faces of greed, aggression and
insensitivity. Dale writes that he knows what the loss of a family member must feel like. He welcomes being “associated” with these caring people. And he states their generosity has provided “good persons” with a second chance. Dale also cooperates in establishing a face for the donor family that is sincerely committed to the deceased (allowing time for them to “heal from the magnitude” of their loss, the “most trying time of their lives”), strongly contrasted to the callous or evil people that populate news reports, and deserving of the “peaceful salvation” of knowing their decision was kind and fruitful rather than unfeeling. Nor does Dale ignore the faces of the transplant professionals who are “fabulous” and supportive, allaying fears they might be less than ethical. Dale felt “proud” of this letter, one might argue, because it worked not only to claim positive social value for himself, but also to proffer suitable “lines” (Goffman, 1972, 5) that others might take up in building their own faces.

When Dale received from his transplant co-ordinator an answering letter from the donor family, his immediate response was not curiosity, exhilaration or trepidation but overwhelming relief stemming from the knowledge that the ritual had indeed “interacted”:

I don’t know, I don’t know who it is, but I don’t think I need that. All I needed to know was they received my letter, and that’s all, that’s good enough for me. Without even reading it.

AM: did you wait thinking ‘maybe I’ll hear from them, I hope I hear from them’?

I was hoping that I would hear from them, but I also, in the same breath, um…as long as I know they received it. And I didn’t know that until I received that letter, in my hands, cause I know that there was a contact.

So I think the whole, like—Arlene, I think this whole process was still lingering out there, for me. This whole transplant, nothing, it wasn’t complete yet for me at all until I received that letter.
In one sense the face-work – and indeed the transplant itself – was complete when the expressive order disrupted by transplant had been ritually corrected, when the positive evaluation of one’s own face and the cooperative venture of preserving the face of others had been communicated and acknowledged.

Goffman (1972, 19) explains that just as the appeal of “Excuse me” is answered by the acknowledgement of “Certainly”, a threat to face and the re-establishment of ritual equilibrium involves two or more moves. When that second move of acknowledgement is not forthcoming, transplant’s rite of decorum can flounder. Kidney recipient Teresa, who wrote an equally heart felt and perceptive letter to the family of her donor, related: “I wrote a letter that they [transplant officials] said was a particularly lovely letter. But I didn’t hear back from them.” When I asked if she had hoped to, she responded simply “Yup”. Her disappointment was palpable. “I will probably write them again within the next year or so,” she stated and added, in deference to the ‘face’ of her donor kin, “Pain [is] still pretty big after a year when you lose a child.”

Although Dale declared that the interaction was complete without even having to read the letter from the donor family, he did nevertheless read it. Not, however, without considerable apprehension. “They gave me that letter down in Toronto, the nurse [at the transplant clinic] just handed me this letter… Never opened it. It feels so [inaudible]… I thought, ‘I’m not going to be reading this here…I’ll read it where I love it the most’.” The letter sat in Toronto, unopened, for more than a month. At the cottage, more days passed. Finally Dale decided, “Tomorrow’s the day. ‘Letter day’, I said.” And he laid it on the bedside table. That night he dreamt of a dark haired male, approximately his age, standing in his room: “just an average guy, an average look; just an average expression,
not mild, not frowning”. It was his donor. “I knew that right away; I said that when I woke up. I said it right away when I woke up.” And that morning, Dale walked down to the dock, letter in one hand, beer in the other (“just to get me through some of it”), and read his letter.

Why did he hesitate? Certainly, the rite demanded its proper setting. And perhaps even the auspicious appearance of his donor. But in all rituals of interaction, the drama lies in the willingness or unwillingness of participants to join in the convention, to take up the lines proffered and sustain the faces being presented. Goffman (1972) noted: “The individual must rely on others to complete the picture of himself of which he himself is allowed to paint only certain parts” (84). Would the donor family defer to the compassionate, caring self that Dale presented? Or hint at his brazenness to profit from their loss? Would they hold the noble demeanour he asserted on their behalf? Or would their raw grief come keening through the pages?

While some recipients protest that not knowing the identity of their donor makes this letter exchange difficult if not impossible, I would argue more specifically that not knowing the donor makes the ritual dance somewhat inscrutable, the ritual outcome unpredictable and the risks to face markedly higher than in “everyday” interactions. Deemed by organizers a ‘letter of thanks’ all the recipients I talked to were acutely aware that this was also a letter of condolence. The formalized patterns of each genre are well known, the ‘lines’ and ‘faces’ associated with each widely disseminated. But their conflation generates an awkward ritual hybrid. “One thing I haven’t been able to do,” kidney/pancreas recipient Kendra told me,
is to write a thank you letter to my donor family. Even though people say you should write it in the first year, I think that the family needs grieving for the first year, that’s my personal belief. And a little bit of that guilt thing. Like I didn’t want to say, ‘Hi, how are you, I’m healthy, thank-you, sorry to hear about your loss’ type of thing.

Further, Kendra related,

I need to know some minimum. I need to know if it’s an English speaking family or a French speaking family, because it’s Quebec, right?...In French you have to know, well in English too, him or her, right? So he [transplant co-ordinator] told me that it was a man, French-speaking man, and the second one’s a French-speaking woman. I thought that was fair enough, type of thing. But had written the letter in English. Can’t write in French, can’t find the right words. And even—like I’m not sure if I’m writing to a daughter, a husband, a mother, a friend.

Although bilingual, Kendra found shaping the delicate references to one’s own face difficult without the facility of a first language. Concurrent was the difficulty of projecting a comfortable and close fitting visage for an entity whose most basic shape cannot be determined. It can be done, as Dale demonstrates. But his long and cautious approach to opening the donor family’s letter indicates how risky such dancing in the dark can be. Ultimately, one does not know if the donor family are the ‘kind’ of people predisposed to follow the not quite set conventions and borrowed etiquettes. This quality of anonymity would not be resolved even if the donor had a name.

Kendra also felt uncomfortable with what Goffman calls the “avoidance practices” (1972, 16) that such rites of decorum demand. “The first year after my first transplant,” Kendra related, “I wasn’t healthy. So I didn’t think I could write an appropriate letter and say, ‘hey, life has turned out.’” To write of the ordeal precipitated by her pancreas transplant – the loss of sight in her one remaining eye (happily regained) and the irreversible loss of kidney function (necessitating her second transplant) – would be, Kendra recognized, inappropriate. It could potentially undermine the very thing such a letter attempts to construct, a positive interpretation of the family’s decision to donate.
Goffman (1972) notes that interaction ritual frequently demands an actor “leave unstated facts that might implicitly or explicitly contradict and embarrass the positive claims made by others” (16).

Although Kendra found such an omission too large or too awkward to make, I did encounter such protective manoeuvres. Hearing about my research at an academic conference, one of my peers strongly suggested I contact his father, Jim, a heart recipient who felt strongly that his transplant carried spiritual implications. Jim had discovered the identity of his donor and he and the wife of the deceased regularly kept in contact. For many months, whenever she discussed the death of her husband, the donor’s wife spoke of it as a farming accident. One of the difficult moments of that relationship, Jim’s son told me, was when she revealed that her husband had actually committed suicide. When I later interviewed Jim the subject of the donor’s death came up. “It was very tragic,” Jim told me. “A tragic farming accident.”

To conduct this ‘face-work’, to write the letter to the donor family, requires several things then. An awareness of the possible negative symbolic associations that transplant carries for donors, recipients and professionals is a motivating factor. Considerable facility with composition is required to blend the conventions of thank you letters and condolences. The recipient must have, or be willing to tell, a story that cooperates with the donor family’s need to build positive social value. Having initiated this ritual interaction, the recipient must be willing to accept the risk that the lines ventured in support of theirs and the donor family’s faces might not be taken up, indeed, might even be countered – a risk compounded by the impersonal and unfamiliar nature of
this decorous exchange. Goffman (1967) writes “the surest way for a person to prevent threats to his face is to avoid contacts in which these threats are likely to occur” (15).

For Dale the risk paid off. “They started off their letter by thanking me!” His voice is stalling with tears and struck with awe.

They thanked me! That’s a miracle! They thanked me for helping them get through it. They said it was at a low point in their life when the letter arrived…it said, ‘it lifted our spirits. Your letter lifted our spirits.’ And then they said regarding the donor, their loved one (they always referred to it as their loved one), that that person was a caring individual who was always giving and sharing and who would always put out for others in need…And that just boosted me, you see. O.K! Well that’s who I’d want to receive it from, somebody like that. And when I read that, I thought—like I read the whole letter then I went back and I read that part.

The response from Dale’s donor family offers resounding assurance that his donor has bequeathed to him an organ and a ‘face’ resplendent with attributes Dale strives for in his own life. Indeed the letter, “miraculously”, offers a ‘line’ even beyond Dale’s hopes--he is not merely “associated” with these caring people, they have accepted him as part of a circle of caring, thanking him for his thoughtfulness in lifting their spirits.

Goffman (1972) would stress that the donor family have not only given Dale an honourable face, but a face that he is obligated to maintain (9). Dale described the receipt of his organ as both a new beginning and a new responsibility, and the receipt of this letter as confirmation of a transformation he had intimated even earlier.

AM: so did you feel changed after the transplant, then?

[Long pause.] Um, yeah, I felt there was a new beginning. And then, a new direction now.

AM: what is it, what’s the newness? How do you describe it?

I think it’s—like the things that would really irritate me before, they don’t now. The day-to-day aggravations, anything like that, they’re too trivial. Yeah, sure I’ll get upset, that’s natural, but it doesn’t affect me like it would. I’d react differently to situations now.
Where I’d be maybe quick tempered to voice my opinions, now I take a little different approach. I think a little bit more before I react now.

AM: why do you think that is? What is it that’s giving you this new outlook? Where’s it coming from?

I think it’s from somewhere inside. I think it’s like I’m kind of living for the donor too. I’m living for now, it’s me, and I’m living for the donor. And I think that’s a big part of it. I think the organ, I think very strongly that somehow, someway—yes, it’s a kidney and a pancreas—but somehow that person, part of that person is somewhere inside of me. I think that’s very much a part of it now. So it’s not just me now in this body. It’s me, but now there’s an addition…

AM: you welcomed it?

Yeah. Yeah. And now, as of Tuesday, when I read the letter from the donor family, even more so.

Dale’s experience with transplant’s rite of decorum is ostensibly a successful one. He has navigated the difficulties of scripting both gratitude and condolence, of crafting lines of positive social value for both himself and for the family of his donor. His face work has elicited the requisite acknowledgement and it is one that works with Dale to restore the expressive order that transplant has threatened, one that conjoins Dale to renew his commitment to a demeanour befitting both himself and his donor. But despite these powerful accomplishments, there is still ambiguity.

“Decorous action marks the rhythm of social occasions”, writes ritual scholar Ron Grimes (1995). And occasions, he explains, “are moments of crossing a social boundary [that] demand a ritual bridge” (45). Greeting and leave-taking are pre-eminent examples, he suggests. Without question the transfer of organs from donors to recipients crosses social boundaries; the decorous letter to the donor family is the officially sanctioned ritual bridge. What no party in the transaction has clearly determined, however, is
whether the letter closes or opens doors. Even in the most successful exchanges this ambiguity can be discomfiting, as Dale’s musing makes clear:

And then, you know, ‘you can write to us anytime’… ‘We think of you often’, they said. ‘We think of you often.’ ‘Please’, you know, ‘please let us know how you’re progressing’. So I think I will. At some point…

So now there’s a connection. A connection made, an actual physical connection. Like I thought maybe…they want to meet me. I thought that was going to maybe happen. How will that go? … And I would want to do the right thing. And be cautious and protect—protect them. But I think I would want to meet them. If they asked me to, I would. I don’t think I would maybe jump at it…I would probably have guidelines. But for me, I would want to bring them up here! But maybe you’re not allowed to, I don’t know.

Just as it conflates the normally distinct genres of letters of condolence and thanks, this rite of decorum is oddly ambivalent about whether it petitions participants to make acquaintance or permits them to fondly part.

I have argued that Goffman’s theory of ritual interaction offers a viable window into this central rite of organ transplant, but there are cautions. Goffman meant to illuminate the rituals of everyday exchanges, yet there is nothing ‘everyday’ about the letter recipients write to their donor family. The donation and receipt of cadaver organs is a momentous event. In applying Goffman’s insights I am not in any way suggesting that either transplant or its rituals have become routinized. Nor am I suggesting, as Goffman’s work has sometimes been interpreted (see discussion in Collins 2004, 21-23), that recipients who write to their donor family are not motivated by very real emotions they feel about their transplant and toward their donor and that family.9 When I commented on the power of Dale’s signature line, “Passionately written with continuous tears of joy, love and remembrance, one lucky and fortunate multiple transplant recipient”, he told me:
That’s how I wrote it. Yeah, that’s how I wrote it… that’s what I was thinking! I was thinking ‘joy’ because look at me now, I received a transplant. ‘Love’, love for my family and love for them and love for my team, my transplant team. And then remembrance for the donor and their family. And I’m lucky. I am. Lucky and fortunate.

Indeed, what first arrested me when speaking to recipients about this letter was the level of emotion they expressed. People who had written it often spoke of the experience as “cathartic”, “meaningful”, “important”. But people who had not written it tended to express equally strong emotions: of regret, obligation, frustration, desire. I tried to describe to a friend what convoluted emotions the letter raised for many recipients, both those who felt compelled to write it and those who felt compelled to avoid it. “Sorry, I don’t get it,” he responded unequivocally. “Why can’t they just say thanks?” The value of Goffman’s work is that it reminds us that “thanks” is not the individual act of saying a few words. It a complicated ritual of call and response, an interaction of two (or more) parties, each carefully monitoring and adjusting the reflection of their personal hopes and fears in the mirror of each others, and society’s, eyes.

Ritualizing

“We were sitting out here on our porch,” George began, and there is the impish gleam about him that suggests yet another outrageous anecdote to be told. It has been an evening of stories, of wild laughter, a little wine and some very candid disclosures (my own included) about the desires, disappointments, pain and revelations that accompany couples who try to love their way through organ failure, especially those willing to enter the thickets of donating and receiving an organ. We sat in Candice’s living room, a pizza box away from each other, oblivious to both the tape recorder and the lateness of the
hour. Eight months ago when the transplant of George’s kidney to Candice had taken place they had shared her home. In the aftermath of the transplant they had parted. But they had sorted, soul searched, scouted each other (trading over 1000 emails!) and now were seeking what George called a rebuilding and Candice labelled “a new beginning”.

“We’re sitting out here on our porch. And it isn’t going well.” George’s delivers this understatement drolly. “And I said: ‘Listen -- if you feel that way, give it back!’”

“That’s fine! I’ll call the hospital and you can take it back!” Candice willingly snaps out her lines. The image of these two middle-aged, accomplished and insightful adults squabbling over the kidney like schoolkids over candy has us all in stitches. When we sober up, George concludes: “We could not get past the hurt and the anger and the pain. And it was my history, her history, just not working.”

One of the largest obstacles was how very short the history of their union was. In May of 2001 Candice is told that the transplanted kidney she received some 12 years ago from her older brother is ceasing to function. Her life in those 12 years has been healthy and full, but she remembers vividly what life was like before the transplant. Desperately afraid that the oncoming illness and exhaustion will trap her in a marriage she has long considered ending, Candice uses a small inheritance from her recently deceased father to purchase a modest home and move herself and her two teenage children. With the failure of the transplant in view, it is a risky move emotionally and financially as her employment as a teacher’s aide is contractual, without any disability or drug benefits.

But Candice has always been open to risk, opting for transplant when it was still a relatively new medical technology and delighting in her precarious pregnancies, the first while in almost total renal failure and the second while a transplant recipient. Her
determination to leave is perhaps even more pronounced because the independence she
craves is threatened. Diagnosed with renal failure at seventeen (a diagnosis she feels
should have been made considerably earlier), she was a very “sickly child” and her young
adult life was circumscribed by ten years of eroding kidney function until she was
deemed “sick enough” for the transplant. “Having to rely on other people my whole life”
is the history she works both from and against.

Installed in her new home, her second marriage over, Candice declares herself
“sworn off men!” But in September of that same year, she meets George, also divorced
and a fellow parishioner at the United Church she attends. He is bright, witty, idealistic,
passionate about the spiritual journey he is on -- and quite persistent. Their attraction,
they both maintain, was sudden, strong and deeply rooted in a shared spiritual
commitment. Their connection grows even faster than Candice’s health declines. Weak
and tired, she begins peritoneal dialysis in January. “It wasn’t an easy life, that’s for
sure,” she related. “It certainly affected every, every aspect of my life… It kept me alive,
basically. It was the option to dying.” Her son was considered as a donor, but rejected.
George watched her languish:
Worse and worse and worse, worse, worse. And the helplessness of it all. And you see
her spirit falling away. You see the ragged—all that stuff. It left her very tired. And
then to watch her fighting it, saying ‘no, I don’t need my nap, I can do this’.

Within 18 months of meeting Candice, George decides he will donate his kidney
and begins the tests to determine his suitability. But he has qualms. Not qualms about
his desire to alleviate the suffering of the woman he loves, but qualms about the
disruption of his own body and about the solidity of the unit within which this transfer
will take place, qualms amplified in this case by the newness of their relationship.
Healthy all his life, with the exception of a bout with polio so early in his childhood that he has only the memory of his recovery, George worries about the loss of control the surgery demands, and the never experienced pain and bodily alteration it will bring about.

“You get edgy,” he explained:

Most of the time I don’t feel very good unless I’m calling the shots. I know why I’m doing it. I know why I’m doing it. But it’s still frightening stuff. This is scary stuff… I found it necessary to create a bubble around me. If you start thinking about this, you will lose it.

George’s sense of apprehension was a marked contrast to Candice’s eagerness. Sick, tired, and aware from past experience how transplant might alleviate this state, Candice ached to move forward. Knowing firsthand both the procedure and the period of recovery she relished neither. But she didn’t fear them. George’s continuing sense of a body disordered and Candice’s seniority in these realms of bodily transfiguration was made clear in this discussion:

G: I remember standing in front of the mirror saying ‘what is that God awful scar?’ I mean, I’m pristine, now I’m not!!…It’s not going to get any better either. It’ll stay pretty raw and rough…It’s not like the scars that she has from the—

C: dialysis?

G: no, the baby

C: caesarean?

G: caesarean, thank you. Those are little—you can’t feel it. Mine’s never going to go like that.

C: yes it is
G: well, it’s hard to see
C: yeah, but they’ll be hard to see on you too
G: yeah?
C: yeah. I mean you can hardly see my first transplant scar, 20 years ago. It’ll fade.
G: he [surgeon] said to me, ‘you’re always going to have this silver mark’
C: well, you’ll have a mark. But it won’t be red like it is now.
G: cause it looks funny, that mark.
C: oh, yeah. But it won’t be like that after years.

In the months preceding the transplant George also worried, as did Candice, about the growing number of tensions in their relationship and their mounting inability to resolve them. Trying to fuse two families of teenage children with a relationship that had taken off very quickly and on the heels of a divorce was a challenge that was seldom satisfactorily met. The constant attentions of extended family concerned about Candice’s health became another point of contention. Chronically ill with renal failure, acutely and seriously ill with periodic infections from the peritoneal dialysis, Candice had the will but not the energy to hash through endless conflicts. George’s frustration climbed. Some weeks before the scheduled transplant he confides to the hospital’s transplant coordinator: “I’m not sure that our relationship is going to make it through the transplant.”

They are immediately called to meet with the transplant team. However, the objective is not to evaluate their relational health or even their emotional health (no counselling or therapy is even suggested, an omission George and Candice bitterly regret), but to ascertain their continued suitability for transplant. This is readily done.
“We were able to convince them that we were OK with it,” Candice related. “And on one level, yeah, we were OK with the fact that our relationship might not make it.” Both the transplant officials and the couple seemed willing not only to sever the kidney from the body that contained it, but also to conceptualize it as disconnected from the lives it was enmeshed in. For the transplant officials to do this they need only pull closer the curtains of a biomedical worldview. For the couple to do this they needed a worldview of a very different sort.

“There are no coincidences,” both George and Candice frequently maintained. And George felt strongly that God had led him to meet Candice when he did and revealed to him what his role should be in her life. This sure knowledge was what carried him past the fears of the surgery and the anguish of their unravelling relationship.

We were walking down the street. I remember stopping her near the bottom and saying, ‘I can tell you now that I’ll be your donor’. She asked if the transplant centre had called. ‘No, no they haven’t.’ But I now know there’s an up [inaudible] and I’m being told. Not that I heard a voice. There’s just—as you grow spiritually you learn that you will get messages…you pick up… There are only so many people who can do what I did. It’ll challenge you. But God knew that I could do that. He said, ‘George, you can do this. And because you can do it, I’m going to ask you to do this. And you just have to do it on faith.’

It is a moral as well as a cosmic vision that sustains the donation:

Things were really rough between the two of us. Some really tough, tough stuff went on. But the idea of saying, ‘I don’t like you any more and you’re treating me rather badly (or at least I think you are) and therefore I’m going to reconsider this’, like you can bail out now—no, I can’t. I can’t do that. Maybe other people can. I can’t do that.

The transplant takes place. But the aftermath reveals that human lives and human body parts are more inextricable than either party thought. Transplant is in, not beside, relationships.

Wow! It’s tough – I can’t move. I’m not in control. I can’t get up. I’ve got to get a nurse to pick me up and to do all that. And I really wanted some support. I wanted her to
come to the room. She’s up—not running up and down the halls, but she’s
moving…And I woke up. I called her twice. Not seeing her at the end of the bed. Why
aren’t you over here? Even though I looked like Alice Cooper, hadn’t shaved and all
that, come and hold my hand and tell me I matter. And that didn’t happen. And I was
just furious. Absolutely furious.

Anxious to tax neither party with worry or demands at this delicate stage, transplant
centres almost always allocate donors and recipients to separate rooms post-transplant.
One can appreciate this cautious logic, however, a longing for contact punctuated many
of the stories I heard from donors and their recipients. George and Candice were explicit
that the long corridors between them in the hospital only lengthened the distance they felt
from each other. The steady parade of visitors to the room of the newly resurrected
recipient rather than the ‘healthy’ donor also left George feeling alone and forgotten.

The irony of carefully separating the parties in the hospital is that they are
released to recover together, simultaneously, from major surgery. Neither is well enough
to be a caregiver for the other, but often – especially in the case of spousal donation – no
other caregiver is in sight. High doses of mood altering immuno-suppressants heighten
the drama. Candice relates:

He ended up staying here which was really not a good idea. I feel like shit and so does
he! And not being very nice to each other. Like really, really being snarly and nasty and
not being able to reach out to the other person.

The transplant also complicated the designation of their relationship, tacking
‘donor’ and ‘recipient’ onto an association heretofore described as friends, partners or
couple. For Candice part of the difficulty of the label ‘recipient’ was the fear that it
altered a relationship of parity to one of dependency.

I guess I knew that was the one thing I couldn’t do on my own. That I had to rely on
someone else. Be it George, be it a cadaver, be it a niece – whatever. I knew from
experience I couldn’t do that on my own.
“I want to tell you,” George interjects, “seriously—

She was absolutely furious. That I’m going to be a donor, because now ‘I have to depend upon you’…And the inability to be grateful, that she sees as beholden, that’s tough for her. I’m not being unfair…Two weeks ago was the first time. There was a phone call saying thanks.

Candice concurs and describes the moment where gratitude for her recaptured energy and abilities flooded over her and prompted her to pick up the phone. “But,” she adds, “part of that is cause you couldn’t accept [thanks] before that.”

George’s conflict over wanting to be thanked and resisting it stems from the equally complex nature of the label ‘donor’. George scoffed when I related the comparison of donors to the Good Samaritan that inflects much of the Christian literature. And he emphatically rejected the designation of ‘hero’. Indeed, his account of the pain, fear and ambivalence of donating underscores the very real emotional needs of the ‘healthy’ donor such labels would deny. Nevertheless, the sense that he has begat something momentous is irrefutable.

To watch the energy – it came back very, very quickly, the curve was very steep – uh, that was just!! And you know then that you’ve done something.

Knowing that there’s part of you in that person, I still haven’t processed all that yet. I remember the first time she said, ‘give me your hand’. I thought I was going to fall down!

“But fortunately,” he adds in typically wry fashion, “we were in a park where it was fairly dark so she couldn’t see what was going on.”

The pain of their constant conflict, bitter estrangement, and unresolved roles reached its zenith. Three months after the transplant George arrives at the centre for his post transplant check up.

It was a tough, tough day. I did not want to go there. I did not want to go to that floor. I remember getting to the counter and I knew the lady behind the counter and so ‘Hello’. 
‘Oh, you’re a donor.’ ‘Yup.’ ‘Well, who was your recipient?’

And I remember looking at the floor and muttering. I couldn’t say, ‘I was Candice Young’s donor’. It was just—grim….terrible.

They had to do something. In this sentiment they were united.

They informed the transplant centre of their distress and counselling was arranged. Candice and George were directed to separate social workers and after several independent sessions a disastrous joint “mediation” affair took place, each arriving to the table with their respective advisors in tow. That final fiasco sent George seeking therapy with a counsellor outside the hospital. Eventually, Candice joined him there. They came to realize that part of their healing would necessitate holding the transplant centre accountable for their failure to recognize and provide for the emotional needs of donors and recipients.

Counselling should be offered and encouraged from the onset of the transplant work up, they insist, and they cite as inadequate the “15 minutes at most” that each spent with a social worker who assessed their psychological candidacy. They are particularly aggrieved that they had to inquire after such resources themselves and that they were not advised of counselling services even when they confided the difficulties they were experiencing. They are unimpressed with the qualifications of the counsellors they were assigned: “very nice women,” George remarked, “but sending us to social workers rather than therapists or psychologists is like sending in nurses to perform heart transplant”. And they resent the tactics of separation and mediation that were employed, models that derive from designates of ‘donor’ and ‘recipient’ rather than ‘couple’. Their attempts at redress have occasioned letters and meetings with both the transplant centre and the hospital ombudsman.
Documenting and sharing the trials of the transplant, the love that fuelled it and
the lessons they learned from it is another of form of redress that entices them. Although
they had yet to begin it, George and Candice described in some detail the book they were
planning to write, the audience they were writing for and the impact they hoped it would
have. They wanted people to know “we moved mountains”. In the plural subject (and
joint authorship) a new frame can be intimated. Even if it never gets written, this
imagined work of composition played a role in their shifting assessment of the transplant,
their roles and their relationship.

Undergirding these determined attempts to heal was a careful reconsideration of,
and a renewed commitment to, the spiritual scaffolding that ignited their relationship,
directed its course towards transplant and sustained them both in its aftermath. They
attuned their reading to new spiritual ideas, as George illustrates:

After the transplant we slowly, slowly began to mend and put it together. I don’t do
waiting all that good. And Candice was saying ‘Go slowly, please.’ And that’s not my
strong suite. But there was a chapter in the book she gave me after the transplant that
talks about waiting. He talks about the number of occasions when Jesus asks people to
wait. He gives the biblical references, but the idea is plain… While God’s asked you to
wait, and you’re waiting, you just don’t wait. He works on you while you’re waiting.
It’s not empty time at all. And so reading that, I said ‘of course’.

They constructed a careful path of prayer that called on God for comfort, support and
guidance but avoided direct petition, as Candice illustrates:

Be with us. Give us the strength that we need to get through this time. It’s really tough;
we’re struggling. Everybody’s stressed; it’s a really difficult time… You’ve got to help
us through this one. Whether I lived or died, that wasn’t even considered. It was ‘give us
the strength’.

They also left the United Church they had both attended for many years, finding
their spirituality growing past the horizons it offered and finding the parishioners unable
(and unwilling) to understand a transplant that strayed so far from the normative script.
George joined a local and liberal Mennonite church. Candice, preferring to define herself as spiritual rather than religious, did not seek an alternate congregation. Both forms of religiosity were complemented in the gift Candice settled on to commemorate the transplant. “It was so nice”, George related,

To go and look at this one and look at that one, and she took the Bible off the shelf and opened the page and there it was, on the left hand side: ‘prepare for relationship’. We just stood there with our arms round each other. We’d just been told. That’s what you do… We would not have recovered emotionally without a spiritual base.

At the time I interviewed George and Candice they were also constructing a commemorative occasion, a mutual statement rather than a gift, a carefully staged illumination rather than an unexpected sign. “Do you know about pinning?” George asked.

Pinning. It was girls and boys. If he put a pin on you, you were going steady sort of thing. It was a 50s and 60s thing. My era more than hers, we joke around about that.

The National Kidney Foundation of the United States has a pin. It’s a year old. Looks like a United Church crest. One half says ‘I gave the gift of life’ and the other half says ‘I received the gift of life’. I saw the pin and ordered one. I showed it to her—‘what do you think?’

Some months later, on the anniversary of the transplant, the pin, with its direct reference to transplant, its vague resemblance to a Christian symbol and its nostalgic connotations of love and commitment, became the central symbol in a rite of transplant they had, literally, fought to get to. I was very honoured to be asked to witness it.

On that June day, a little self-conscious about my clothes (what does one wear to a transplant pinning rite?) and my role, I made my way to the locale the couple had finally settled on. Several had been considered: the transplant floor in the hospital, a little quiet waiting room, the hospital’s stately chapel. In the end, the Mennonite church that George was finding increasingly inspiring was chosen. George was there when I arrived,
arranging the carefully chosen flowers, and Candice appeared moments later, petite and feminine, a pretty shawl over her dress and her auburn hair gleaming.

There was only the three of us. They were sure that an officiate was not needed. They were reluctant to incorporate the tensions that their respective children, still uncertain about the reconciliation, might bring. They considered inviting select people that had been important parts of the experience, but decided “no. This is ours. This is what we’re going to do, for and with each other.” The intimate sharing of our evening together positioned me close enough to their story, yet distant enough from their everyday affairs, to be an enlightened but impartial witness. Ostensibly, my job was to take pictures but I suspect I provided a human, as well as a digital, register.

Standing face to face at the front of the church each took a turn reading a scroll containing their carefully written declarations to the other about the experience they’d undergone. I didn’t record their words then or later, but Candice’s final phrase so encapsulated her pert and youthful features, her zest, energy and frankness, that it seems as easy to remember as her name: “Thank you,” she said, “for letting me stay up late.” When a scroll had been read, its owner rolled it back up and sealed it with a tightly tied ribbon. They then handed this piece of themselves to the other to guard.

The declarations complete, each stepped forward to affix the appropriate half of the pin to the other. Like the kiss after the ministerial pronouncement of marriage, this action drew them physically closer, glowing, awkward, emotional; a squeeze of hands, a fumbling with lapels, a glimmer of tears.

They closed the rite by taking turns reading a passage aloud from the Bible, heads together over the large book on the lectern. In total the rite took maybe 15 minutes. It
was direct and simple, befitting the open, unadorned sanctuary they chose, and perhaps an apt inversion of the drama and storm of the transplant itself.

What did their rite do? It is tempting to think of it as a rite of healing, release of the anguish of past months, realignment into parity and union, balm to their battered relationship (this is the kind of ritual healing that Driver (1991) elaborates). But in fact the work of ‘healing’ had been done in the months prior to the ritual: counselling, conversing, imagining, challenging and eventually arriving at a healthy enough understanding and a healthy enough rapport that such a rite could be enacted. Perhaps participants can step into conventional rites and ritual systems with resentment, disbelief or oozing wounds and, in the hands of established knowledge, neutral directors and practiced gestures, step out whole and new. But it is unlikely that participants in the throes of chaos can invent, direct and enact their own ritual healing. Healing in this ritual was more of a performance – a condensing, embodiment and display of movement past chaos and scars that were healing.

It was also a performance of revised expectations. “It shouldn’t have happened to us,” Candice said of their tumultuous transplant experience.

C: Cause it’s not right. It’s not the way it should be. It should be a wonderful experience! It should be something that’s so special and so –

G: And it didn’t happen. What did happen? What we’re experiencing now is much richer than anything we would have experienced.

C: Yeah.

The transplant experience “ought” to have been wonderful. That was their expectation. The reality turned out to be far different. “Ritual,” states Jonathan Smith’s (1982) oft-repeated phrase, “is a means of performing the way things ought to be in conscious
tension to the way things are”. Certainly, the rite they constructed played out what the transplant ought to have been, an affirmation of love and a physical, emotional and spiritual rejuvenation, against the incongruous backdrop of what actually transpired.

But what ‘ought’ to be and what ‘is’ are neither as static nor as distinct as Smith might lead us to believe. With the collapse of the commanding narrative of what transplant ‘ought’ to be about -- heroic donors, grateful recipients and organic union -- Candice and George not only lament the incongruity between what ought to be and what was, they also construct new ‘oughts’. Professionals ought to attend to the gamut of transplant emotions. Organ exchanges ought to be between friends and lovers, brothers and sisters, parents and children, not ‘donors’ and ‘recipients’. Bonds ought to be cultivated in the hospital, waited on patiently at home, and sheltered by spiritual belief and practice. They declare these new imperatives even “richer” than the previous ones. What ought to be is not simply a ‘given’. If it were, there’d be little incentive to construct new rites. Ritual, then, not only performs the tension between two established and opposing conditions, it debates what those conditions are. Having wrestled with their incongruous transplant, George and Candice’s rite, in some small and imperfect way, makes present what they say transplant really ‘is’ about.

It would be remiss to suggest that the ritual was solely about their transplant. Clearly, it was also a celebration and a prediction of their continued union. Our evening together had been peppered by unfinished sentences and innuendos about marriage. If they were afraid to speak their hopes the pinning spoke for them, its setting, symbols and gestures rehearsing a more familiar rite of relationship. This ritual magic did not
transpire. They ended their relationship two years after the pinning, five years after it commenced.

I maintain a sporadic, but genuine, affiliation with both of them. When I asked Candice what finally drove them apart, she replied: “Money. Kids. The question of marriage. You know, the big ones.” Transplant was no longer on the list. On that issue they had, as George liked to put it, “done the work” and the ritual they constructed was part of that work.

I would like to think, however, that the ritual did more than work through issues. In life’s jumble of events and dramas, people and relationships, comings and goings, much slides together and not much stands still. In the quiet of a Mennonite church on a fine June morning the rite they lovingly undertook set the donation of George’s kidney and Candice’s receipt of it outside the grist of existence.

Ceremony

Police officers, at least 100, in uniforms of varying colour and insignia, but with synchronized bright boots, white gloves, and tidy short hair. They stand at attention in long parallel rows down the centre aisle under the soaring arches of the Cathedrale Saint-Michel in Sherbrooke, Quebec. It is this image that captures most succinctly the curious blend of state and religion that infuses the annual ACDO Organ Donor Memorial Service, arguably the largest organ donor recognition event in North America.

ACDO, the Association Canadienne des Dons d’Organes, has a twenty-year history of organ donation advocacy. The group raises funds for emergency organ transport vehicles and coordinates the voluntary service of police officers to drive them.
The close association with Quebec’s police forces colours the group’s other mandate: to honour Quebec’s organ donors through an annual memorial service and a permanent Cenotaph in the city of Sherbrooke. In the dozen years since their inception, Quebec’s organ donor families have enthusiastically adopted the Cenotaph and the ceremony. Of the 275 organ transplants conducted annually in the province, approximately 200 families each year participate in ACDO’s commemorative activities.

Such popularity suggests that organ donor families find some meaningful expression of their loss, their donation, and their loved ones in the ritual gestures of ACDO. Congregants were sombrely and formally dressed and arrived well in advance of the four-hour service. Many held copies of an ACDO newspaper insert published that day in the Sherbrooke Tribune and distributed freely at the entrance to the Cathedrale. This feature section presented statements from various dignitaries, including the mayor of Sherbrooke and the Provincial Premier, and showcased (in contradistinction to the anonymous tribute favoured by many organ donor memorials) the full name of every organ donor being honoured at the ceremony. After the ritual entrance and seating of the honorary patron, Her Excellency the Lieutenant Governor of Quebec Mme. Lise Thibault, the ceremony commences with a series of formal speeches, interspersed with religious and inspirational music performances, building to its ritual climax: the individual proclamation of the posthumous title ‘Ambassadeur de la Sante’ for each and every organ donor.

At the calling of their loved one’s name, family members representing the donor are escorted by a police officer down the main aisle of the church to the sanctuary where they receive, ‘á la main de Mme Thibault’ as all of the press releases describe it, a
commemorative medal resplendent in a velvet jewellery case and engraved with the donor’s name and newly awarded title. After an intimate word with Mme Thibault, donor representatives exit the platform. They are given a floral tribute to place on the memorial table and are asked to sign a memorial book. Their police escort returns them to their place in the pews and rejoins the constabulary queue in the centre of the church.

At the close of over 200 presentations, a priest leads the congregants in responsive prayers and the recitation of the ‘Our Father’. But Catholicism doesn’t have the last word; that is reserved for the bugle sounding Taps, a requisite moment of silence and a stirring rendition of ‘O Canada’. The service concludes with the official exit of Mme Thibault, after which the congregants make their way across town to the Cenotaph. In a Sherbrooke city park, encircled by pine trees and provincial flags, they seek out the imprint of their loved one’s name amidst the now many hundreds of names inscribed on the black marble slabs.

Eulogized but not evoked, individuated but not personalized, the dead have a uniquely public persona at the ACDO memorial service. What connection does this memorial service forge between donor kin and their deceased loved ones? I saw, in many varied images of grief, people’s enduring loss. The stories of donors and families were enacted, not narrated. The loss of a mother embodied in the faded blue jeans of a teenager shuffling sullenly behind his dignified father and uniformed escort. The loss of an adult child captured in the cane and hesitant walk of an elderly man. The loss of an infant made tangible in a baby photo placed in a cameo broach and pinned to the lapel of a sobbing mother.
But I also noted, with some surprise, undeniable moments of pride and excitement, reflected in people’s carriage, their animated acceptance of the medal, their enthusiastic sharing of it upon return to their pew. “If their eyes often fill with tears expressive of their pain, they shine equally with pride as their hands reach to accept the remembrance,” writes Mme. Thibeault in her note to the Sherbrooke Tribune.

Quoting examples ranging from the effigies of kings to the well-dressed corpse in contemporary funeral services, Hallam and Hockey (2001) argue in their book *Death, Memory and Material Culture*, that monuments and other commemorative practices acknowledge the temporality of the physical body, but insist on the persistence of a social body. Commemoration works to hold the dead in the social spaces of the living, thereby maintaining relationship with the living. It is the social body of donors that the ACDO ceremony and cenotaph promote and preserve. Donors are extolled as exemplary citizens, ambassadors, to whom society owes their gratitude and respect. Their stable social place is marked in metal for relatives to cherish and in stone for a community to remember. Disseminated in the press like those of the illustrious, read aloud in the cathedral like those of the saints, their names are sacralized and spread, from cathedral to cenotaph, through the city and beyond. The ceremony rewards the generosity of donor kin by awarding to the donor social capital, social standing -- a social body -- with which both donor families and the wider community can interact.11

But it is not just discrete social bodies that are delivered by the ACDO memorial service. In its ritual movements, symbols and gestures the ACDO ceremony births (or at least sends out the announcement of) a communal body. Not all scholars agree that public commemoration is a socially integrating process, however, there can be little doubt
that one force of monuments and memorials is religious and civic exhortation.\textsuperscript{12} ‘Sermons in stone’, Alex King (2001) dubs the oratory capacity of memorial media; they are inscriptions that inscribe. Through its epitaph of organ donors as fallen soldiers and its insistence that organ donation generates not just health, but a healthy collective memory, the ACDO memorial service promotes an intercorporeal citizenry and carves a nation from the exchange of their organs.\textsuperscript{13}

Although never spoken, the ritual equation of the organ donor to the soldier who gives his life for his country is marked.\textsuperscript{14} The police in dress uniform and drill formation are immediately evocative of the military. The choice of commemorative medals, not encased in plastic like a collector’s coin, but hung on a ribbon is an unmistakeable reference to bravery and sacrifice. The erection of a cenotaph, rather than a tree, bench, plaque or any of a host of commemorative objects used to recognize organ donors, is likewise a clear echo of soldiers lost. Even the cenotaph’s strategy of listing each donor’s name can be read as a citation of the influential Vietnam War memorial. The recurring theme of ultimate sacrifice, giving one’s life for the nation, is evoked not only by tangible references, but also by the omissions of the ACDO memorial service. Although live donors account for almost 50\% of all organ donors in Canada, the ACDO ceremony neither invites nor acknowledges them. It is not simply the act of donation that ACDO wishes to elevate, but specifically the cadaveric donor, the citizen-soldier in whose death can be sought the meaning and renewal of the state.\textsuperscript{15} Organ donation is a posthumous sacrifice.\textsuperscript{16} The soldierly accruements of the ACDO ceremony do not assert that organ donors died for their country. But they do intimate the corollary: that theirs is a country worth dying for.
The ACDO memorial service even grafts the nation onto transplant’s familiar ‘gift of life’ metaphor. In ACDO’s ritual translation, the generous ‘gift of life’ given to recipients transmutes to a precious legacy of health given to all of Society. “Sign your donor card, transmit with us a heritage of health”, entreats ACDO’s promotional material. “The medal given to organ donors is a just token of recognition not only from recipients, their parents and friends, but also from all of Quebec”, states Jean Charest, Quebec’s premier. “The giving of an organ is an act of generosity and of human solidarity”, adds Quebec’s Director of Police. Organ donation, claims the ACDO memorial service, engenders not only a healthy recipient, but also, a healthy civic union.

The displacement of the transplant recipient as the primary beneficiary of the donor’s largesse is ritually underscored in the ACDO memorial service. In sharp contrast to many organ donor recognition events, organ recipients at the ACDO ceremony are witnesses, not participants. Directed upon entry to the choir loft, they sit far removed from the activity of the cathedral floor, trading transplant stories amongst themselves as they watch the drama unfold below them. The identity of the group is announced by a banner that stretches across the choir balcony, identification more or less invisible to the donor families who face the altar. Segregated and cloistered they have an uncertain and unfamiliar role to play in the transplant narrative of civic genesis that ACDO favours.

The portent of this celebrated nation was clear. Hymns, prayers, clerics and cathedral are overt references to the sacred import of the persons being commemorated and the communal body being regenerated. More implicit is the Eucharistic rhythm embedded in the ceremony’s order and movement. Like a Catholic mass, the ACDO service begins with the procession of the celebrant. Confined to a wheelchair since
youth, Mme Thibault is wheeled down the main aisle flanked by a select group of
officers, after all the congregants have been seated. As in the mass, the ritual apex is the
bestowing of a potent talisman that confers transcendent memory and social belonging.

Even the distribution of the medals intimates Catholic liturgy. The halting
advance of parallel lines of penitents down the centre aisle. A brief lingering over each
individual as the medal is handed from Mme Thibault to the recipient who bends toward
her wheelchair. Exiting, participants turn once more toward the altar to offer in homage
their floral tribute. When every partaker has been administered to, both mass and
memorial close the rite with offerings of thanks, musical praise and the formal recession
of the celebrant. Instinctively grasping the Eucharistic structure of this ceremony,
participants and organizers relate the highpoint of the ACDO memorial as the ‘incredible
moment’ when the Lieutenant Governor of Quebec presents the medal ‘from her hand’,
‘with a personal word for everyone.’ Whatever the state of ‘belief’ after the Quiet
Revolution, Quebecers still reside in a habitus of the mass. They are at home in its
currents; their bodies know its codes. Religion lives in the familiar movements of this
ceremony, consecrating the organs proffered, the families that donate, and the state that
accepts the offering.

What to make of ACDO’s curious mix of organ donors, dead soldiers, religion
and nation-making? In what follows, I want to elaborate on the motifs of the ACDO
ceremony as central to an emergent civil religion, a civil religion that promotes and
sustains a particular project of biological citizenship.

Whereas Durkheim (1965) argued broadly that rites were the core means by
which a social group periodically reaffirmed itself, ritual scholar Ron Grimes (1995)
specifies that ceremony is the ritual mode most conducive to solidifying group allegiances and identifications. “Ceremony invites the participant to surrender idiosyncrasies and independence to some larger cause, for which one is willing to fight, die, or pay homage” (47) and can “easily become the core of a religio-political system” or “civil religion” (48).

I argue that this service is a rite in an emerging civil religion, a sensuous civil religion that ties the sacred to emotions, sentiment and the organic body. While I borrow Bellah’s (1970) term, my account of a sensuous civil religion is indebted to sociologists’ Mellor and Shilling’s (1997) description of sensual solidarities. Sensual solidarities are communities founded on what is emotionally, organically and sentimentally common to all. They are forged by blood commitments and by the embodied practices of “keeping warm together”. The sensual solidarity is a notion of the collective that contrasts sharply with understandings of civil society as a contract between rational, ordered individuals. A contractual form of society inculcates the cognitive apprehension of hallowed ideals that disciplined bodies can and should uphold. A sensual solidarity inheres in a corporeal intimation of the whole: commonality is revealed through the senses and bodies are seduced into collective orders of meaning.

The sensual solidarity is a form of association that, if we are to believe Mellor and Shilling, is currently re-emerging. In late modernity, they argue, ‘disciplined bodies’ are here and there giving way. Their re-formation in sensual forms of sociality prioritises “tribal fealties” over individual contracts (Mellor & Shilling 1997, 162). They are quick to point out that sensual solidarities have not vanquished, but cohabit with, rational, contractual civil society. Organ transplant is a particularly compelling example of the
‘new baroque’, the sensual body cast in a modern web of individual rights, formal rationality and civilized associations.

In North America the staunchest symbol of the social contract in the exchange of organs is the ubiquitous organ donor card, the contractual document that allows individuals as rational, informed owners of their bodies to consent to the release of its organs. But, as many scholars have attested, transplanted organs cannot be contained by the rational and the contractual. Indeed, the very technology of transplant challenges the bounded, classic Renaissance body, evoking instead Bahktin’s grotesque, for only porous, unfinished, dying and regenerating bodies can offer or incorporate organs. It is the grotesque body that is immanent in sensual solidarities Mellor & Shilling state (1997, 174). Further, transplant makes palpable our commonality. Literally, we are as one, the technology proclaims. And in organ donor recognition services such as ACDO the shared emotions of trauma and tragic loss are laid over the blood ties already forged, deepening the sense of an organic collective.

The sensual solidarity that is generated at the ACDO ceremony incorporates many of the themes that Mellor and Shilling discuss, but resembles none of the examples they put forth. Unlike Mafia, urban gangs and football crowds, groups small enough to genuinely ‘keep warm together’, existing almost as points of resistance to the larger civil society, the ACDO service stretches its tribal fealties to the borders of the nation. Like Bellah’s (1970) civil religion, the civil religion centred on organs aspires to solidify, engage and envision a republic, not a local brotherhood. But this civil religion is not nearly so cognitive as the one Bellah describes. Nor can it be traced to Rousseau’s Social Contract. It doesn’t speak of ethical principles; it stresses the commonality of being
human. It doesn’t reflect a people’s religious self-understanding; it invokes an epiphany of shared emotions. It doesn’t narrate itself through historical persons and battles; it collects itself through the bodies of its members, living and dead. It doesn’t rely on familiar sacred stories; it moves itself in habitual ritual gaits. The sacred is not “the light of ultimate and universal reality shed on American experience” (Bellah 1970, 186); it is the effervescence of a collective that senses - emotionally, organically and sentimentally - its unity.

Scholar Stuart Hoover (2002) locates a new American civil religion materializing at national sites of commemoration such as Ground Zero in New York. He describes a contemporary merger of media and religion that inspires mass pilgrimage to such sites and elevates them to iconic status. I agree with his claim, but think that bodies keeping warm together at public commemorative sites, citizens joined by the common sentiment of bereavement, the nation recollecting itself through the bodies of its living and its dead is not just a ‘new’ but a sensuous civil religion. Likewise, it is the non-cognitive nature of visual media, their reliance on emotional communication, their appeal to the senses, their championing of the consumptive rather than the disciplined body that make the media such an effective partner in national mourning (Mellor & Shilling, 1997). It is the media’s sympathetic sensuality as much as their powers of dissemination that allow them to invoke sensual solidarities across the country.

Civil by dint of its aspirations, sensuous by dint of its affectation, the sensuous civil religion is effectively, but not exclusively, affirmed in ACDO’s commemoration of organ donors. The rite has oratorical echoes in a wider discourse about the civic importance and unifying function of organ donation (see for example Prottas 1994, 172).
This is not the sole discourse organ transplant produces (see discussion of this and other discourses in Chapter 5), nor is ACDO ‘representative’ of organ donor rituals. But it is a powerful drama and motif, particularly in Canada and specifically in Quebec, because it aligns with an important aspect of Canadian identity, allegiance and vision: its commitment to public health care.

Scholars of religion are generally unanimous that a Canadian civil religion does not exist (Bellah and Hammond 1980, Kim 1993) and their rationale for this void rests comfortably on a much more widely discussed deficit: the lack of a distinct Canadian identity. Kim (1993) argues that any number of factors mitigate against “a common understanding of the ‘Canadian Way of Life’, of Canadian identity, and of national purpose” (258). He points specifically to Canada’s divided federation, its long history of two cultural “solitudes”, the conflicted response to symbolic registers such as “land”, “north” or “mosaic”, the dominance of American culture products, the failure to generate, despite valiant attempts, a distinctive Canadian cultural industry, and the rejection of potential national icons (for example the RCMP) as too rooted in British colonial power and the rejection of others (for example the bilingual anthem) as too rooted in French language politics.

Only in Quebec, religious studies scholars argue (Kim 1993, O’Toole 1996), can anything resembling a civil religion be detected. Lemieux claims that Quebec’s muffled Catholicism contributes to a “diffuse churchless faith which simultaneously supports a vague, almost subliminal, civil religion of reassuring familiarity and a privatized popular religion” (quoted in O’Toole 1996). And Kim (1993) argues that French Canadians in
the province of Quebec have “their own distinctive set of beliefs, values, symbols and other cultural attributes that serves as a form of civil religion” (258).

Yet despite the denials of a distinct Canadian identity and a pan-Canadian civil religion it is routine to assert that Medicare, Canada’s social program of public health insurance, is complicit in both. Perhaps most centrally Medicare “represents a way ‘we’ differ from ‘them’” (Rutherford 1998, 193; Begin 2003, 179), differentiation from Americans being de rigeur in the Canadian search for self-identity. However, our machinery of government, system of education, tax structures, immigration laws and other aspects of social and political policy also differ from the U.S., but such differences rarely find themselves framed in the hallowed terms that Medicare is. The most critical acknowledge healthcare as a “national icon” and a “source of national pride” (Paquet 2003) and the most committed describe it as “a key expression of the principle of solidarity”, a legislative act of “icon status” (Begin 2003, 179, 180). It is held sacrosanct, allegedly above the transactions of the market, and gives Canadians, one observer claims, a feeling of “intrinsic moral superiority” (Begin 2003, 179, my italics). “The public funding system embodies a view of the relationship between the individual and the environment”, another analyst states (Evans as quoted in Begin 2003, 179). Canadians’ self-perception as healers and care-takers may inform their performance on the world stage as peace-keepers and aid workers. The widely held opinion that Canada’s system is being eroded or challenged (or proving inadequate) was scrutinized in the recent Romanov Commission on the Future of Health Care in Canada. The Commission elicited tremendous citizen input and considerable media fervour; one indicator, perhaps, of how pervasive (if not unanimous) this national vision is in Canada’s public sphere.
Such descriptions suggest that Canada’s system of public health insurance is both a symbol of and force for Canadian unity and identity, yet also reaches to be ‘something more’: a domain of policy, practice and representation capable of articulating our aspirations for the kind of nation and people we want to be. It is enshrined in artefacts of iconic status (the Canada Health Act), celebrated in collective rites (such as ACDO), recollected in national legends (such as the story of Tommy Douglas and the ascent of the CCF) and embodied in the acts and person of civic heroes – Terry Fox a figure of adulation and emulation for two decades now (Harrison 1985) with antecedents in figures such as Norman Bethune and growing accord that organ donors deserve to join this illustrious company.

There remains much to explore in this tentative assertion that public healthcare, and by extension and example the practices of organ donation and transplant, might function as (or assume the vestments of) civil religion in Canada.24 But certainly the American accent on the legal system as the emblematic structure and protectorate of the civil religion (Hammond 1998, Cole & Hammond 1992) is untenable in a country where even the constitution can’t generate much accord. The imperative for religiously plural nations to articulate and cultivate allegiance to common but non-traditional systems of meaning may be at the root of civil religion in both countries, but in Canada the universality of bodies has proven a more workable touchstone than the universality of ‘blind justice’.25

How to assess this sensuous civil religion, the emotive public commemoration that typifies it, and ACDO’s civic rite of mourning in particular? Lock (2002) muses that organ donation might profitably be reframed as a bequest to society rather than a boon to
an individual recipient (372). Certainly the ACDO ceremony does this. In the sensuous civil religion of organs, it is the nation that receives the gift of life. Sharp (2001) laments the propensity of organ donor recognition services to erase individual identity and paper over grief with “green” metaphors of life and renewal. Certainly the ACDO ceremony offers a corrective. On a broader scale, scholars have theorized a decline of public mourning and explored the impact this has had on both individual and collective psyches (see for example, Homans 2000). Certainly the ACDO ceremony works publicly and diligently to offer deceased donors ritual passage through social states.

But if the ACDO ceremony represents departure – from typical donor memorials and dominant constructions of the ‘gift’ – it can also be seen as the extension and reinforcement of a particular citizenship project that Nikolas Rose and Carlos Novas (2005) see as increasingly pertinent to late 20th century society. Stressing the vital role that biology (race, intelligence, ‘blood’, stock) has had in the construction of citizens, definitions of nations, and associated logics of inclusion and exclusion, Rose and Carlos (2005) define the most recent articulations of biological citizenship as fundamentally tied to the new conceptualizations of biology introduced by biomedicine, biotechnology and genomics. They describe the new emphasis of citizenship projects (health promotion), new varieties of citizen collectives (societies of patients and experts), new types of political activism (around health research and health resources) and new kinds of subjectivities: “whereby individuals faced with new kinds of biomedical technologies and choices must shape new ways of understanding, judging and acting on themselves, and must engage in a kind of re-imagining of those to whom they owe responsibilities” (2005).
The ACDO ceremony inculcates this sense of a civic identity tied to biological rights and responsibilities. Its equations of soldiers and organ donors, its epitaph of a legacy of health left by donor “ambassadors”, is an evocative translation of a venerable project of biological citizenship (whereby citizen-soldiers sacrificed their lives to protect the vitality of a nation largely defined by race and ethnicity) to an emergent project of biological citizenship where the “health of the nation” rests on transplant technologies and the cultivation of a ‘donor subjectivity’ in order to safeguard a nation largely defined by its commitment to the vital life of its subjects. Rose & Novas (2005) comment on the way political interest in the health of the population today is less dependent on notions of “population unfitness” for the struggle between nations, and more concerned with the moral imperative to reduce inequalities in health. “Geopolitical rivalries” frequently centre on international comparisons of the “extent to which nations have instituted successful policies for the governance of health” (63). Canada’s determination to increase its organ donor rates per capita to levels comparable to other Western nations is a case in point.

Organ donation is a particularly viable technology for the project of biological citizenship. Many of the biocitizenship projects and biosocieties that Rose describes form around a biological conception of a shared identity; group identity rests on a specific biomedical classification. In Rose’s estimation these biosocial groupings can sometimes fall prey to ‘identity politics’, contests about the priority and righteousness of their own particular “states of injury”, but they can also extend across national boundaries and encompass something of a ‘global citizenship’. Transplant’s biosociety differs. It is inherently formed around a specific biomedical classification, however, the call to arms
for citizen-organ donors has no classificatory limits. It can be expanded to the borders of the nation -- anyone can sign their donor card -- but can expand no further than the nation. While only some might become ‘soldiers’ who make the ultimate sacrifice, all who affirm their allegiance to this biomedical technology can be counted as supporters of the national citizenship project.

It is interesting to bring into conversation the ‘sensuous civil religion of organs’ and transplant’s project of biological citizenship. The former -- an attempt to solidify and envision the republic with recourse to corporeal intimacy, emotional vulnerability and commemorative ritual -- is enriched with an understanding of the power of biomedicine and the projects of governance that “make up citizens” (Rose and Novas, 2005). The latter -- an updating of the confluences between biology, nations and citizenship -- is enhanced by the idea that rites and religion, not just rights and responsibilities, also bring citizens into being.

Conclusion

Transplant rituals have complex objectives far exceeding the production of more organs for transplant. They are not always ‘religious’ (although they borrow heavily from liturgical rites), but they are certainly a central -- and public -- component of the social, ethical, emotional and physiological dramas engendered by transplant technology. The rites of transplant perform private emotion in public spaces, weave personal reception with public discourse, and produce both individual ritualized actors and social collectives (citizens, nations and transplant communities) defined by their ritual knowledge. Schechner (1974) argues that ritual is a particular kind of performance, one
that privileges efficacy over entertainment, and participants over spectators. He describes performance as a continuum, with ritual at one end and theatre at the other. This chapter has explored the ritual end of that continuum. The next chapter explores the theatrical side of transplant: the performance of transplant’s sanctified narratives and the portrayal of its sacred symbols in a variety of popular media.

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1 It would certainly be possible to consider organ failure the breach and organ transplant the ritual redress, in the fashion of Robbie Davis-Floyd’s (1992) work on hospitalized birth as a ritual process. Although exploring the ways the surgical transplanting of organs itself is ritualized would no doubt be fascinating, it is beyond the scope of this chapter. Here, organ failure and organ transplant are seen as breaching normative physical, psychological, social and spiritual boundaries and the performative acts and symbolic gestures of recipients are seen as redress.


3 My view adds another dimension to Sharp’s (2001) observation that a transplant “ideology” “unites a diverse array of parties into a self-defined transplant community” (366).

4 My categorization of the transplant rituals described here is indebted to Grimes (1995) articulation of the modes of ritual sensibility (Chapter 3) and his discussion of nascent rituals (Chapter 4).

5 The subject of ritual clowning at camps for the chronically ill is a fascinating one that deserves further exploration.

6 The statistics on how many recipients write letters to the family of their donor are not published. Both my own and others (Lock 2002, Sharp 2001) ethnographic research suggests that a significant number do not write such letters. However, the narratives demonstrate a thorough awareness that such a ritual exists. The fact that many who decline to participate feel a need to explain their reluctance arguably demonstrates the ‘weight’ of this ritual in the exchanges of organ transplant.

7 And given the media discourses about organ transplant that surround all three parties they would have to be somewhat obtuse were they not aware of such possible interpretations. See discussion in Chapter 5.

8 See Lock 2002, 40-41 for an interesting discussion of the hybrid status of the brain-dead donor. It would seem that transplant lends itself to all sorts of hybrid states.

9 Goffman himself stressed that spontaneously expressed feelings were inherently part of the rituals of interaction, they spoke eloquently about the attachment we feel to our face and that of another, and they serve to further the ritual interchange (1972, 23).

10 Equally stressful is the role of the healthy person in a household where two others are recovering from donation and transplantation. “My mother nearly went crazy,” related Graham, a liver donor to his father.

11 Hallam & Hockey (2001) caution that the social body can preempt the subjective body/person in communities of commemoration. This is precisely Sharp’s (2006) fear about donor memorials. However, the desireability of maintaining a social body goes some way to explaining the continued participation of donor kin in such memorials, and shifts the focus away from an antagonistic frame that pits the desires of procurement personnel against the desires of donor kin.

12 See the debate in Forty & Kuchler, 2001.

13 The question of “which” nation – Quebec or Canada – the ACDO ceremony seeks to solidify is a complex one. The service was conducted in French at a Catholic cathedral -- clear nods to Quebecois culture. And the preponderance of provincial politicians on the platform could be read as a strong endorsement of Quebec’s sovereignty. Further, organ transplant benefits, almost exclusively, citizens of the province as organs only travel outside provincial boundaries in rare and extreme cases. However, healthcare in Canada is one of the country’s most elaborate experiments in federalism. While the provinces
(as the entities that deliver and regulate healthcare) retain considerable autonomy, the federal government dictates the broad principles of public healthcare and contributes the funds to administer it.

14 See also Sharp’s (2006) discussion of the predominance of the soldier motif in commemoration of organ donors (134).

15 Marvin & Ingle (1996) draw on Rene Girard’s theory of religion to assert that nationalism is a religion that draws totemic power from the death of its soldiers, yet hides the true impetus for this sacrificial death from itself. In contradistinction to Benedict Anderson’s notion of imagined nations, they assert that communities of blood, not textual communities, are the heart of the nation. The ACDO service’s deployment of the soldier motif suggests that sacred nations require both blood and imagination.

16 This is a debatable claim given disputes about the legitimacy of the brain-death designation (see Lock 2002) and the plethora of medical interventions that take place prior to death in the case of donation from non-heart-beating cadavers (an increasingly acceptable source). Organ donation also relies on the willingness of donors to declare their intentions prior to death. My objective in calling organ donation a posthumous sacrifice is to distinguish between soldiers, whose willingness to sacrifice for the nation is the cause of their death, and donors, whose death or imminent death is not a consequence of their willingness to sacrifice organs.

17 These quotes are translated from the ACDO special insert published in the Sherbrooke Tribune, 2000.

18 This was the arrangement in 2003, in 2000 an alternate, but still segregated, seating area was arranged for transplant recipients who’d traveled to Sherbrooke for the 1st National Transplant Games.

19 These phrases are from conference organizer Sylvie Lauzon who I spoke with by phone.

20 O’Toole (1996) discusses how the Quiet Revolution displaced the Catholic church from its pre-eminent role in various fields of activities and prompted the exodus of Quebecers from its pews. Nevertheless, he argues, Quebecers still overwhelming identify as Roman Catholics and receive explicit instruction in the Catholic faith through the parochial school system. Catholicism survives as a “cultural matter”.

21 Consider Sharp’s (1995) discussion of the extended biographies of organ donors that recipients construct and the professional assessment of such imagined accounts as “irrational”, perhaps even psychotic. See also Fiedler’s (1996) description of the cultural narratives that subtly influence our unconscious perceptions of transplant. See also Schepers-Hughes (1991) accounts of the independent life of organ stealing rumours.

22 In fact, the ACDO service contrasts starkly with the attributes of organ donor services as Sharp (2001) describes them: dependent on “green” metaphors of growth and renewal and hostile to identifying individual donors. I certainly witnessed rites that more closely follow the script Sharp outlines; the commemorative service hosted by the Trillium Gift of Life Network in Toronto with its ritual dictate of “completing the circle of life” would be a case in point. The ACDO ceremony is unique in part, as Hogle (1999) reminds us in her study of organ transplant in Germany, because culture, context, history and geography influence the construction of rites. So do the “accidents” (Smith 1982) of ritual: ACDO’s ritual deployment of Quebec’s police forces is both the reflection of civic aspirations written onto organ donation and the happenstance of Sherbrooke’s Chief of Police being deeply moved by the failure of a close friend’s kidneys.

23 I am indebted to William Clossen-James for pointing out this affinity.

24 “Only in government-sponsored polls or political harangues does [the rhetoric of universal healthcare] ever get confused with national identity and citizenship” states Paquet (2003, 80). But as Rutherford (1998) points out in relation to Canada’s bureaucratically orchestrated and enormously flawed project of growing Canadian culture, appearances can be reality. Drawing on Baudrillard he argues the simulation of a genuine Canadian culture can have real affects.

25 Bodies, Marvin and Ingle (1996) point out are “the raw material of society” (771).
On a dull and drizzly day in February 2004, I found myself parading down a quarter mile stretch of Bloor Street between Dufferin and Dundas with about sixty high school students, a small police escort, a rather large press entourage and a smattering of dignitaries. The march was in honour of Kristopher Knowles, a 14-year-old boy awaiting a liver transplant and the centre of a media campaign to promote organ and tissue donation in Canada. “Kristopher’s Wish,” states the promotional brochure, “is to give hope to men, women and children who are waiting for the precious gifts of life.” To this end, Kristopher had been “trekking” across Canada, appearing at sporting events, festivals, malls and especially schools in over two hundred cities. ‘Kristopher’s Wish’ is modelled on popular Canadian health promotion campaigns that have featured the afflicted walking, running or rolling in wheelchairs across the country to publicize their cause. Kris’ health, his age and the fantastic pace of his appearance schedule – 200 cities in less than 365 days – entailed motorized travel between cities and symbolic walks in them. The march down Bloor Street was one such walk.

The parade was launched with a formal assembly at Bloor Collegiate Institute, a rather august old west-end high school built in 1925. The student body is extraordinarily diverse; a recent influx of Asian and south Asian immigrants augment the neighbourhood’s more established Portuguese population (City of Toronto, 2003). It was a large and varied group of students that filed into the school’s auditorium as the speakers took their seats in a semi-circle on the stage. Around the edges of the amphitheatre the city’s media set up shop: television teams, photographers, and press reporters. A
documentary film crew drifted among them. “I’m here for something. Something about something,” a Toronto Sun photographer inquired of the school secretary as I waited in the office prior to the event. “I just woke up,” he added ruefully. The event in itself is not particularly newsworthy, but it has registered on the media’s radar due to the scheduled appearance of the Provincial Ministers of Health and Education, and the concerted publicity efforts of the Kris’ Wish campaign manager, George Marcello.

George Marcello, himself a liver recipient, is an ardent supporter of organ and tissue donation. After his transplant in 1995, he felt compelled to advocate for those still waiting. Under the auspices of his charitable organization ‘Step by Step’, George made an inaugural walk from Toronto to Ottawa in 1997. An Ontario wide campaign followed in 1999, and a Canada wide campaign in 2000-2002. One purpose of these walks was to raise public awareness about the shortage of organs and the plight of those waiting. Another was to press for legislative measures to address this situation. A veritable promotional whirlwind, there is little doubt that George has achieved his first objective. His website claims over 4000 media stories documenting the “steps” of his campaigns (www.stepbystep.ca). Political support, however, has been more elusive. Smiling photo ops with public figures from the Premier to the Prime Minister to the Pope failed to produce the political will, public funds and specific measures (most notably presumed consent legislation) that George felt the issue demanded. “Crushed and heart-broken,” he nevertheless stepped out again, this time with young Kristopher Knowles. The Knowles family had made George’s acquaintance at one of his rallies. Kris felt keenly the passion of George’s mission; Kris’ parents no doubt shared his sympathy for the plight of those waiting.
A slight man, with a dark complexion and a direct manner, George darts between the media, the office and the backstage prior to the assembly’s commencement. Simultaneously and with equal intensity, he organizes the search for a missing tape recorder, the minutiae of the next event and the groundwork for subsequent campaigns. On stage his nervous energy finds its target; he is an engaging speaker and a dynamic presence, if a bit theatrical. After lengthy thanks to his supporters and promoters, George calls upon the speakers.

“Hello, I’m Duncan Corry and I’m alive.” Tall, slim and fit, a strikingly handsome man in his early fifties with a touch of grey and a slight Scottish burr, Duncan introduces himself as a retired police detective and relates the rapid and near fatal progression of his liver disease. “But…” (there is a slight dramatic pause) “…my story has a twist.” Here he bends the narrative sharply. “I received a miracle. My son Graham donated 60% of his liver and saved my life.” Now the story sings. Duncan articulates his regained health and his deeply felt gratitude. He refers to Graham as a hero, but notes that Graham rejects this appellation and sees the doctors as the true heroes. He closes with an appeal to his audience to at least think about donation, even if they elect not to participate. “Don’t take your organs to heaven,” he admonishes, “heaven knows we need them here.”

Duncan’s testimony is followed by a sober speech from Darwin Kealey, CEO of the Trillium Gift of Life Network, Ontario’s organ procurement agency. He enumerates the people waiting, dying and donating every year. He informs the students about the organ donor card they will receive with their driver’s licence. He instructs them to
discuss their wishes with their families. Kealey’s low-key pragmatism contrasts sharply with the delivery of George Smitherman, the provincial Minister of Health.

“Here’s a young man,” Smitherman booms, gesturing toward Kris, “who isn’t well but has found his own inner strength. He has found his power! He’s making something happen for all citizens everywhere! We should have more people like him!”

“But you too,” – now he gestures expansively to the audience – “can take power over your health. You can make this a more healthy society. By not smoking, not drinking and driving, not eating too much, exercising – and signing your donor card!” He jokes in an aside that eating too much is his personal demon. He reads a letter from Premier Dalton McGinty praising Kris’ initiative, his drive and his social commitment.

“You have power here”, the Honourable Minister reminds the students, “power over yourselves, power for our future, power for a healthy future!”

The minister’s rousing speech stirs something. The students begin to sense their affinity with the fair-haired innocuous boy who sits centre stage. George Marcello is quick to capitalize on the momentum. He proceeds with a lengthy introduction to Kris, the most heroic person he has ever met, who has inspired the most admiration he has ever felt, with the most contagious smile he has ever seen. Not even the twenty serious operations he has undergone trying to salvage his failing liver (here Kris lifts his shirt and the scars are pointed out) have jeopardized that smile.

“He is just like you,” George announces. “He likes hockey!” There are cheers. “He likes the Leafs!” Even greater cheers. “He likes eating!” Strangely, this too draws cheers. “He likes Edge 102.1!” This elicits a chorus of cheers and jeers depending on musical preferences. “He likes Xbox!” This is the capper; the audience erupts.
“Who here remembers Terry Fox?” George inquires. Hands go up. “Terry Fox had a dream, and his dream was $1 per Canadian to go to cancer research. Now we have another young man who has another dream, and his dream is to have everyone in Canada sign their donor card!” To wild applause, Kris takes the microphone.

He appears as typical a 14 year-old boy as his hobbies would suggest, his movements self-conscious, his speech laconic. “Hi, I’m Kris (with a K, not CH)” -- his audience gives a sympathetic giggle -- “and this is my dream: that every man, woman and child on the list should get an organ and that everyone should sign their organ donor card.” He tells them that his website is really cool and they should check it out. He thanks them for having him. About to abandon the microphone, he is marshalled back to present a gift to the Honourable Member. A rolled up tube with a bow is produced. The minister unravels a newly commissioned poster, an artistic rendering of Kris – and his Wish.

In soft romantic focus, against a wash of pastel colours, Kris’ youthful face, boyish bangs and wide smile vies with the “Torch of Life” for centre stage. A play on
the Olympic Torch that relays the ‘spirit’ of the Olympic Games to each host city and each new generation of athletes, the Torch of Life was donated by a marketing firm and lit by the Mayor of Toronto at the commencement of George’s walk across Canada. An official ceremony saw the torch symbolically relayed from the hands of the mayor, to the bereaved family of an organ donor, to a mortally ill patient on the waiting list, to George who carried it across the country. The background of the poster shows the bequeathing of the Torch of Life to Kristopher Knowles.

The minister announces he will frame the poster and hang it in a prominent place in his office so that everyone who sees it will be alerted to the need for organs, although it is hard to discern exactly how (other than in the fine print) the poster conveys this message. What it does convey is the innocence of youth, the relentless march of time, and the sentimental bonds that link people and generations, gallantly carrying our collective aspirations forward to a doggedly brighter future. These same passions now crescendo through the auditorium as Elton John’s anthemic “Circle of Life” lifts the speakers off the platform and levitates the students through the exits: “It’s the leap of faith / It’s the band of hope / Till we find our place / On the path unwinding / In the circle, the circle of life…”

In the lobby Kris sits briefly at a table handing out organ donor cards. Students crowd and photographers angle for the close-up. A select number of students have been elected to participate in the march, and this smaller group makes its way outdoors. The Torch of Life leads our procession westward to Bishop Marrocco/Thomas Merton Catholic Secondary School. The gaggle of Bloor Collegiate students around Kris departs,
but his reputation has preceded him—a number of the Catholic high school students seek him out for autographs.

Here the assembly is repeated with only minor variations. The Minister of Education, Gerard Kennedy, steps in for the Minister of Health. The school band has been recruited to play O Canada. A student opens the assembly with a prayer to the Creator on behalf of Kris and his mission. “Normally, we would have had a couple Hail Marys or something,” the principal tells me in an interview afterwards. Apologizing for sounding “dismissive”, he explained that he had deliberately avoided standardized Catholic prayers in deference to any visitors from the public school and in ecumenism with potential television audiences.

Indeed, the spectre of the media and the push of politics have made this event somewhat stressful for the principal. He had originally turned down the school board’s request to have his school commissioned as a stop on the Kris’ Wish campaign. The planners seemed disorganized and the intricate coordination of marching students, disrupted timetables and disparate school boards daunting. The board accepted his regrets, but called back later to say “it’s coming down from higher up: this is a ‘must do’.” The scramble begins. He solicits his student achiever group to promote the event and sequesters enough classes to ensure 200 students in the auditorium. A second call advises him that the minister of education will be making an appearance, press in tow. Anxious that his school show well on TV, the preparations escalate. The entire student body is now invited to create a full house, the band is pressed into service with an hour’s rehearsal, plants are brought in for the stage, and the care-taking staff are scrubbing the front halls to erase evidence of the students’ muddy morning rush. To the principal’s
delight and relief the coveted media image materialized: the school shone, the band rose to the occasion, and the students were “a great group, a great audience.”

The media, it seems, can grant a lot of wishes. This chapter explores the way diverse media foster, perform and disseminate the intersecting (but not identical) desires of transplant recipients, transplant professionals, government officials and their publics. It follows the visual and narrative presentation of organ transplant across a wide range of advertising, publicity, and media-tized rituals, tracking the genre of transplant advocacy of which Kris’ Wish (and the approximately 2000 media citations it spawned) is an instructive example.

Organ donation is a complex project with multiple sponsors. Despite this heterogeneity, public claims are regularly cast in religious language (even by those devoid of religious affiliation). A hodge-podge of Christian references, New Age theologies, moral hierarchies and cosmic schema sacralize organ transplant advocacy: Good Samaritans and citizen heroes, transplant miracles and their testimonials, circles and torches of life, green ribbons and memorial gardens, the glow of candles, the gift of life, and a heaven that wants our organs here. I explore the ways religious language, spiritual motifs and moral discourses construct (and sell) this ‘public good’ and its attendant mode of governance. However, I also explore the ways communal bonds are given moral sanction and a coherent narrative by the sacred themes of transplant advocacy. Drawing on my ethnographic research with transplant recipients (simultaneously producers, consumers and targets of transplant advocacy), I examine the multi-vocality of religious language in public claims-making.
The picture of transplant advocacy I present is neither comprehensive nor overly systematic, however, there was a loose logic to my methodology. I began by taking careful note of advocacy that involved the participants in my study and by attending to the promotional sphere of transplant events I attended. As most of the participants were located in Toronto, and much of my fieldwork took place in southern Ontario, my media review draws heavily on newspaper articles, media rituals, promotional materials, health communiqués and advertisements produced in Toronto and environs. Knowing that organ procurement organizations are the best funded sponsors of transplant advocacy, I sought out the advertising campaigns of Canada’s largest procurement agencies, Trillium Gift of Life Network and BC Transplant Society, much of which is archived on their websites or discussed in corporate reports. (I did not venture into the French language campaigns of Quebec-Transplant.) I also took note of early national campaigns sponsored by Health Canada. I communicated personally with these organizations to verify details about the campaigns. I have included examples of American transplant advocacy where they have been particularly illustrative.

The portrayal of organ transplant in movies, television dramas, talk shows, novels and other genres of popular culture provides an interesting foil to the work of advocates. Transplant’s religious referents express sentiments in keeping with the aspirations of global citizenship: they enjoin the intimacy of strangers, an ethic of human care and a sense of universal equality. These ‘global’ sentiments, however, are always in tension with the ambitions of the nation, the demands of the local and the needs of the individual. The compassion of nations is measured (and compared) vis a vis organ donor rates per capita. Regionally, organ procurement organizations compete for scarce resources. And
an increasing number of individuals barter in a new global marketplace of body parts, where organs follow all-too-familiar colonial trade routes. These tensions play out in the symbolic realm. Alongside the sacrosanct transplant advocacy runs a popular (and powerful) discourse of organs snatched and organs sold. Transplant advocates construct civic identities and religious subjectivities against a backdrop of transplant ‘sins’.  

My concern for the stories and experiences of transplant recipients shapes this chapter as it has others. However, in this chapter I index those stories and experiences to the media milieu that informs and encases them. There is a movement afoot in the discipline of anthropology to recognize media technologies, media products and media spaces (e.g. movie theatres) as inextricable from the embodied lives, cultural meanings and social structures of the collectives anthropologists study, be they localized or diasporic, technologically advanced or tradition bound (Ginzburg 2002, Rothenbuhler & Coman 2005). Acknowledging the reality of “media worlds” is said to challenge the anthropological accent on the ‘exotic’ and the ‘indigenous’ while productively extending anthropological methods and concepts to the complex cultural phenomena we call media (Rothenbuhler & Coman 2005, 1). The “risk” of media anthropology and its interdisciplinary appeal (to students of communication, journalism, sociology and other fields) is said to be a dilution of the traditional ethnographic method such that media explorations stand in for site-based research and media texts for embodied persons (Rothenbulher & Coman, 2005, 2-3).

In this case, however, attending to media discourses about organ transplant has not meant diverting my gaze from the recipient community that is the focus of this study. This group of organ recipients were very active producers, as well as consumers, of
transplant advocacy. Almost without exception, each – like Duncan -- had performed their story (or an aspect of it) in some form of media: newspaper reports, television clips, documentaries, radio call-in shows, magazine articles, websites, media events, newsletters and bulletins, posters and pamphlets. ‘Organ donation awareness’ is a central part of the transplant ‘field’ of these consultants. As I hope this chapter will make clear, it shapes both their identity and their experience in complex ways. Their participation in transplant’s public discourse gave them a practiced ease in telling their story, a religious language to tell it with, and a sense of mission in doing so. Doubtless these factors were (in many instances) what prompted them to come forward and speak with me about ‘religion’ and ‘transplant’.

Also, like earlier chapters, this chapter uses organ transplant as a window through which contemporary religious meanings, practices and experiences can be explored. Having considered Christian perspectives on this medical technology, religious understandings evolving from a (post)modern death, the connections between religious experience, illness and moral identity, and the ritual rhythms of the transplant body, this chapter turns to a sub-field of growing importance in the study of contemporary religion: the intersection of media and religion. The explosion of televangelism in the 1970s and 80s alerted scholars to the importance of the media in analyses of contemporary religion (see Clark, 2004). According to Robert White (2004), the early emphasis on religious institutions and their relationship to the media has given way to an appreciation of religion as cultural practice and as social movement. This facilitated new understandings of religion and media. White argues that one of the central questions in the study of media and religion has been “how people use media to construct meaning in their lives”
Stuart Hoover (2002), whose audience reception studies have been very influential, feels “the media are collectively coming to constitute a realm where important projects of ‘the self’ take place – projects that include spiritual, transcendent, and deeply meaningful work” (2, see also Hoover 1997).

Yet this emphasis on individual meaning-making and self-actualization in the study of religion and media can displace important considerations of power and disregard the limits to agency. Recipients and donors do construct individualized belief systems and moral identities from the media’s repertoire of sacred transplant symbols. However, transplant participants are also interpellated, or hailed, by media identities that are ‘ready-made’, sponsored by social elites, and given moral authority by the religious vestments they sport. There is a complicated solace, for both donors and recipients, in the identities proffered by the media’s ‘religion of organs’.

Finally, as White (2004) cautions, we need to ask questions about the kinds of culture the media build, not just the kinds of identity. I concur with scholars who have noted that the ‘religion of organs’ masks the sale of brain-death and transplant technologies, the creep of commodification to the realm of the body, and the persuasive mode of governance produced by the moralistic marketing of public goods. However, as I hope to show, the religious language, spiritual motifs and moral discourses that mark the media’s portrayal of organ transplant also intercept, deepen and divert a number of identifiable religious currents that stream through contemporary North American culture. The portrayals of organ transplant in the media build religious culture, even as they extend aspects of our consumer culture and transform aspects of our political culture.

Histories

In the early decades of the clinical transplanting of solid human organs (1950s through 1970s), press coverage in the United States was largely an exclamatory appraisal of transplant “firsts” with the largest barrage of media attention reserved for the very public performances of the first heart transplants. By 1958, only a few short years since the first kidney transplants, transplantation had received enough coverage in the public media for “transplant” to become a separate heading in the New York Times Index. In the early 1960s the media chronicled the introduction of dialysis technologies and marshalled support for the public funding of dialysis centres. The media played a significant role in establishing expectations of public funding for the treatment of end-stage renal disease in the U.S, an expectation that later fuelled the public funding of transplants. During the mid-60s experiments with xenotransplants and artificial hearts whetted the media’s appetite and primed audiences for the feature presentation: the heart transplant exploits of Dr. Christian Barnard.

In 1967, in a 5 hour operation at Groote Schur Hospital in South Africa, Dr. Christian Barnard performed the first successful human heart transplant. Details about the donor, Denise Darvell, and the recipient, Leonard Washkansky, were widely publicized (in sharp contrast to the later policy of anonymous donation). Washnasky was followed in and out of hospital, and his own “firsts” (getting out of bed, leaving the hospital) were all documented. He survived 18 days with Darvell’s heart. The immunosuppressant drugs left him susceptible to the pneumonia that he subsequently succumbed to. However, Washnasky’s rapid demise did not interfere with the fanfare
that greeted Dr. Barnard. Media followed every move of the U.S. tour Barnard undertook following the surgery. The apex of the tour was an appearance on the popular CBS news show “Face the Nation.”

The media spectacle of the first heart transplant became a media circus when some months later Barnard transplanted the heart of Clive Haupt, a Cape man of mixed racial ancestry, into Philip Blaiberg, a white South African dentist. Major American networks NBC and CBS clamoured for exclusive rights to the Blaiberg story. A South African freelance journalist, posing as a medical student, snapped photographs from the operating room gallery and scooped them both. The racial overtones of the story, particularly given South Africa’s apartheid state, spawned much commentary: “Haupt’s heart will go literally to hundreds of places where Haupt himself could not go because his skin was a little darker than that of Blaiberg” (Ebony, March 10, 1968 quoted in Johnson, 1989). Clive Haupt’s widow requested her husband’s heart be given back to her to bury with him should Blaiberg require a second transplant. The heart, however, remained with Blaïberg. He died 19 months after the surgery from complications due to rejection.9

In her content analysis of this early press, Johnson (1989) found that “transplantation appeared in the media as a technical spectacle orchestrated by surgeon-heroes. Official bulletins about the patient’s continued survival, abrupt or lingering death, was the touch-and-go stuff of public drama” (117). Detailed descriptions of medical procedures and extended discussions of the uncertain outcome were a constant in news stories about the first heart transplants.10 But, Johnson argues, in subsequent years the media portrayal of organ transplant gradually shifted. Between 1973 and 1986, these same media sources became convinced that transplant success was far less in doubt (118)
and far more dependent on organizational arrangements than technological advancements or skilled physicians (108). The press made less frequent reference to costs and ethical concerns, while individual sentiments (such as feelings of closeness expressed by the donor family and recipient) were mentioned more regularly (119).

One rationale for this shifting script, Johnson argues, was the rise of the Independent Organ Procurement Agencies in the United States. Twenty-two of these independently incorporated agencies were introduced in 1980, funded primarily through the End Stage Renal Disease program. The IOPAs worked alongside the HOPAs (Hospital Based Organ Procurement Agencies) that had managed organ supply for the previous 20 years. The traditional HOPAs were part of the administrative structure of a transplant hospital, directly responsible to a surgeon and working primarily for the transplant centre of the hospital that housed them. The newer IOPAs were governed by a board of directors, managed by an executive director and usually committed to several transplant centres in a geographic region. Marketing was a key mandate. Two markets and two strategies were identified: emotive appeals to the general public and rational presentations to intensive care professionals within hospitals. The IOPAs represented “the first federally-funded ‘marketing organization’ rationally designed solely to obtain and distribute human organs independent of any medical institution” (24). Campaigns for organ donation (including televised public service announcements and bumper stickers with catchy slogans), appeals by the President of the United States and other elected officials on behalf of particular citizens awaiting transplant, and hospital-generated press releases concerning the progress of transplant patients became a familiar part of transplant’s mediascape (74). Between 1980 and 1985 the number of IOPAs grew
from twenty-two to fifty-five (64). Their number, organizational rigour and marketing
mandate contributed to the shifting kinds of “stories” generated by transplant
Regardless of its demoted stature, transplant advocacy has ensured that the technology
retains an active, if altered, media presence.

No comparable analysis of Canadian press in these years exists. However,
veteran recipients with long records of service in transplant advocacy concur that media
coverage of organ transplant has lessened in intensity and shifted in focus. Kate recalled:

When we held the World Transplant Games in Vancouver [1993] – with over 2000
athletes -- TSN gave us 30 seconds. The first year I went [1987], because I worked for
the radio I wanted to get in the media room, right? Two typewriters, one guy. That was
it. Transplant Games! This is big news, right!

But I remember I talked to the organizer of the Games, that started in Britain, Dr. S--.
And he says to me, “You know, the first year we held the Games [1978] you couldn’t
move for media. They were everywhere! And most of them at the finish line. Waiting
for the hearts to run 100m and drop dead.” Sensationalism. That’s what they were there
for. When it didn’t happen…

In Kate’s estimation, transplant’s success precipitated its fall from the front pages and
this is no doubt a fair assessment. Nevertheless, advocacy efforts (such as the World
Transplant Games) have kept transplant in the public eye; indeed, I saw several
community newspaper articles detailing Kate’s success at the 2005 Transplant Games in
London, Ontario.11

The trail of transplant advocacy in Canada roughly parallels the American path
with the following provisos: it was later, looser and less evenly developed. Transplant
medicine in Canada has kept pace with international developments. On occasion Canada
has led the pack. Kidney transplants from living related donors began in the late 1950s;
organs from deceased donors were transplanted in the early 1960s. The first Canadian
heart transplant took place in 1968 in Montreal, the same year Clive Haupt’s heart was transplanted into Phil Blaiberg. Under Dr. Cal Stiller in the early 70s the transplant program at the London Health Sciences Centre became the site for some of the early clinical trials of cyclosporin and a world centre for monitoring and preventing organ rejection. The first successful lung, and double lung, transplants in the world took place in Toronto in the 1980s. However, transplant technologies were not uniformly distributed across the country. The largest provinces (Ontario, Quebec and British Columbia) developed diverse and active transplant programs. The prairie provinces were slower to develop comprehensive transplant programs (even today only kidney transplants are performed in Saskatchewan, and only kidneys and lungs in Manitoba). Likewise, the transplant program in Nova Scotia serves all of the maritime provinces (http://www.transplant.ca/cancon_transprogram.htm).

Organ procurement has been equally inconsistent. No national strategy, registry or co-ordinating body existed until 2008 when the Canadian Blood Services was mandated to expand its operations beyond blood services into organ and tissue donation and transplantation (unlike the U.S. where UNOS has been in effect since 1986).

Provincial procurement organizations along the lines of the American IOPAs have also been slow to surface. British Columbia is something of an exception – BC Transplant Society, an autonomous body coordinating all aspects of transplant in the province and funded by the provincial Ministry of Health, has been in operation since 1986. A similar organization in Quebec (Quebec-Transplant) was established in 1992. The situation in Ontario reflected the long-standing power struggles in that province between governments and professional medical bodies. The Multiple Organ Retrieval and
Exchange (MORE) program (1988) was a joint effort of the provincial government, the Ontario Hospital Association, and the Ontario Medical Association. Organ donor coordinators worked independently of MORE through their various transplant centres while the agency coordinated the provincial waiting list and the limited public education campaigns. In 2002, Conservative premier Mike Harris replaced MORE (or, as it was then called, Organ Donation Ontario) with the more autonomous and centralized public body, The Trillium Gift of Life Network. Very recently (2005) Manitoba followed suit, developing Transplant Manitoba – Gift of Life Program as an independent Organ Donor Organization. The remainder of Canada’s organ procurement agencies function more like the American HOPAs – they are housed in and affiliated with regional hospitals and operate without a clear legislative or marketing mandate.

Given Canada’s lack of independent, federally sponsored ‘marketing organizations’ rationally designed to obtain and distribute organs (and the relatively late blooming of provincial equivalents), early advocacy efforts lacked managerial coordination, sophisticated marketing research and calculated promotional strategies. In the late 1980s and early 1990s, transplant advocacy in Canada was an amalgam of efforts by hospital transplant programs, fledgling provincial procurement agencies, collectives of transplant professionals, health promotion organizations such as the Kidney Foundation, and transplant recipients themselves. In 1987 the handful of lonely Canadian transplant athletes participating in the World Transplant Games in Innsbruck came home determined to organize nationally and return to the 1989 Games with a much larger Canadian contingent. The Canadian Transplant Association (CTA) was born of their
efforts. Under the slogan “Organ Donation Works” they have been long-time grassroots promoters with a notable media presence.

By 1997, change was in the air. A federal act was passed that designated the last week of April “National Organ and Tissue Donation Awareness Week [NOTDAW].” NOTDAW gave a collective focus to the loose assortment of advocacy efforts. More concentrated and collaborative campaigns were mounted, drawing more reliable press coverage. Also in 1997, the green ribbon (used by Americans for some years to symbolize support for organ donation) was taken up by Canada’s transplant professionals and parlayed into a national symbol here (http://www.transplant.ca/aware_initiatives.htm). In 1999 concern about a persistent and growing gap between the supply and demand for organs and tissues generated an influential federal report about Canadian organ procurement efforts (Standing Committee on Health, 1999). Based on report recommendations, the Canadian Council for Donation and Transplant was formed in 2001. An advisory body to the Conference of Deputy Health Ministers (Federal, Provincial and Territorial), the CCDT’s “council of experts” have coordinated, conducted and disseminated research on transplantation in Canada, including considerable scrutiny of Canadian attitudes to transplant and optimal strategies for promoting organ donation.

Not until the turn of the century did transplant advocacy in Canada take on the hallmarks of structured and sophisticated social marketing. The federal government, responding to the reports of the late 1990s, mounted multi-faceted media campaigns in 2001 and 2002 under the auspices of Health Canada. These campaigns featured television advertising (short public service announcements and longer commercial ads), print advertisements and newspaper supplements, websites, posters, and promotional
material (distributed through a partnership with Wal-Mart). The 2002 campaign (based on commissioned Environics Public Opinion Research) reads like a marketing textbook: objectives, target audiences, key messages, tactics, and strategic alliances are all carefully defined (Health Canada, 2002). These were the only campaigns directly funded by Health Canada. After 2002, the CCDT provided surveys, studies and tactical advice to provincial ministers of health who subsequently took up the quest through their provincial procurement agencies. Those agencies with sufficient budgets developed a three-prong approach to advocacy: advertising, publicity and “community partnerships”. The latter involved collaborative programs of outreach with other transplant advocates (health promotion organizations, collectives of transplant professionals and associations of transplant recipients) as well as allegiances with sympathetic corporate and social groups.

One of the problems with these histories, both Johnson’s detailed analysis of press coverage of transplant in the U.S. and my brief sketch of transplant advocacy in Canada, is that they present organ transplant advocacy, and the associated development of bureaucratic organizations seeking marketing solutions to the problem of organ shortages, as a unique case. Most scholars tend to view transplant advocacy in isolation. Consequently, there is a tendency to cast transplant advocacy as the champion of a biomedical worldview and the standard-bearer of the advance of corporate medicine. Transplant advocacy, they argue, not only generates a robust transplant industry but also serves as rhetorical licence and metaphorical mask to the atomization, objectification and commodification of the body.14
But, in fact, transplant advocacy is part of an extraordinarily pervasive expansion of civic advocacy in late 20th century North America and not an isolated project of technological imperative and biomedical persuasion. In *Endless Propaganda*, Paul Rutherford (2000) charts the cultural history of the rise and nature of civic advocacy since the mid-20th century, a rise concurrent with the reach and power of television advertising. In these decades, civic advocacy proliferated across a wide range of promotional fields (corporate, social and political), emanated from a number of elite citadels (not only the state, but also corporations, and increasingly a “third sector” of non-profit and non-governmental organizations) and worked “to fashion and to popularize a dizzying array of new public goods (clean air, family values, the healthy body, women’s rights) as well as to warn against a collection of social risks (such as drug abuse, AIDS, environmental disaster, lung cancer)” (Rutherford 2000, xvi).

Organ donation is one of these ‘public goods.’ It is produced – as Rutherford argues all public goods are produced – through the discipline of marketing (6). Public goods are “products” born of “surveillance” (task forces, commission reports, statistical surveys, questionnaires, polling), “spectacle” (advertising, ritual, publicity, celebrity) and the ‘science’ of consumer marketing (“product, pricing, promotion, and placement”) (6). The logic of marketing – the idea that products can solve problems – has been extended to the social sphere. Social marketing rests on the assumption that “any given social or health problem can be adequately addressed if the right message could be communicated to the right people in just the right way at the right time” (Wallack, quoted in Rutherford, 69). The contemporary public sphere emerges as a huge marketplace of goods and risks in which citizens act, not as rational discussants, but as consumers pitched a sophisticated
sell by social elites who have the resources, networks and skills to mount multi-media campaigns and disperse them across civic space.

The rising tide of civic advocacy and its extensive reliance on the discourses and disciplines of marketing has, Rutherford argues, changed the nature of the democratic public sphere. Sponsors of civic advocacy sought to establish specialized knowledges and managerial discourses, social “truths”, to “exercise power over the ordinary lives of individuals and populations, and for their own good” (93). The overlapping rhetorics and strategies were a loose consortium, not a conspiratorial agenda, but their collective impact has been an expansion of the scope of governance and the collapse of so much that was once private into the public sphere (92-93). The expanded public sphere changes disposition as well as boundaries. Civic advocacy constructs a particular kind of citizen (one whose character is defined by their consumption of public goods) and particular kinds of citizen collectives (recognizable as the “markets” that buy public goods) (95).

Transplant advocacy needs to be seen as part of this continuum, and its rhetorics and motifs analysed as part of the late 20th century restructuring of the citizen body and re-ordering of the public sphere.15 The donation of the organs of the deceased (or living) to their fellow citizens is most assuredly a collapse, an excision even, of the formerly private into the precinct of the public sphere. It is consistently portrayed as being “for our own good” – the good of recipients (the vagaries of transplant rarely spoken of), the good of donors (citizen heroes who ‘live on’ in expanded social circles), the good character of citizens who can now purchase this public good along with others16, and the good of various citizen collectives (the province, the nation) who can display their
cohesion and compassion via organ donation rates per million and vis a vis the competing rates of other markets. When Health Minister Smitherman implores Toronto’s high school youth to take “power” over the future -- “by not smoking, not drinking and driving, not eating too much, exercising – and signing your donor card!” -- it is neither the atomized nor the cyborg body that is being advanced, but a particular kind of civic body, one nourished by the ‘sizzle’ of ‘spectacular’ public goods.

Selling organ donation as a public good is not the equivalent of selling organs. As Rutherford notes,

we are dealing here as much with the analogy as with the reality of the market. Public goods are rarely put on sale. Nor do people necessarily treat them as they do ordinary commodities. Indeed, public goods often have a moral dimension that is lacking in their private rivals: their consumption can involve sacrifice, such as paying more taxes or giving up some cherished behaviour, which is why these commodities often reek of virtue. (Rutherford, 2000, 4-6)

Rutherford finds the images, narratives and themes of civic advocacy “grounded in a moral logic,” excelling at a pious game of ‘honouring’ and ‘dishonouring’ to sell their public goods (and “unsell” social risks). “The art and rhetoric of authority,” he explains, regularly alternates between a moral discourse centred on sin, evil, indulgence, excess and retribution (producing a sense of bodies at risk) and invocations of utopia -- yearnings for a better self and a better world, a world full of saviours and social heroes, harmonious marriages of technology and tradition, and celebrations of our common humanity (94, 268).

These paired moral arguments are indeed the lingua franca of organ transplant advocacy. On the sin side of the equation, official propaganda poses the ailing recipients as the bodies at risk. The fear articulated is one of scarcity and needless death. Counter propaganda positions donors as the bodies at risk and raises fears of organ sales and
organ snatching. But these civic sins have potent correlates. Transplant advocacy has generally reverberated with reminders of human connections, intimations of sacred power, and quite explicit visual and narrative references to religious visions, values and hopes. I turn now to the content of transplant advocacy, to the delineation and effects of its moral logic.

_Citizens, Samaritans and Strangers_

It is ironic that while many transplant scholars argue definitions of brain-death and technologies of transplant have received little or no resistance from religion in North America (Lock 2002, Johnson 1989) transplant advocates expend considerable amounts of time, energy and money combating perceived “religious barriers” to organ transplant and donation. While advocacy organizations are increasingly aware of the need to address misgivings across North America’s religiously plural population, the majority of their outreach efforts have been to Christian congregations. Various marketing materials have been developed to convince the devout of transplant’s affinities with their tradition. In video and voice-over, image and copy, scriptural passage and liturgical posture are superimposed onto appeals for transplant’s legitimacy. This sacrosanct promotional literature has a tendency to travel. It slides between portraying organ transplant as religiously permissible and hailing it as religiously inspired. It migrates from sectarian to secular audiences. And it wanders through the wider promotional efforts of the transplant lobby, leaving conspicuous traces of religious sentiment and symbol.
A particularly instructive example is the slick promotional video produced in 2005 by One Legacy, California’s organ procurement agency. Created as a visual aid for One Legacy staff and volunteers advocating to Christian parishioners, the 2 ½ minute tableau is an emotive meditation on Christianity’s kinship with organ transplant.

The electronic green waves of a heart monitor undulate across a black background, an unmistakable and instantly recognizable symbol of life hanging in the balance. A pair of hands tightly clasped in prayer materializes in one corner of the screen. The soundtrack is measured, solemn, and very much uncontested. Printed messages appear silently on screen. “Heal the Sick.” “Raise the dead.” The Christian intimations are then confirmed: “Freely you have received, freely give. Matthew 10:8”

The ominous rise and fall of the monitor is banished, replaced by a series of questions. What does it mean to give? To give love? To give selflessly? To give Life? To each query there is a scriptural response. Love defined by Jesus’ commandment “to love one another as I have loved you.” Selfless love described as “no greater love than this,” a man “laying down his life for his friends.” Giving life inferred in the transfer of Adam’s rib to Eve.

As the sun rises in the background, successive images make the case for the correlation of selfless, life giving love and organ donation. A beaming middle-aged woman with her hand pressed against her husband’s heart. Clasped black and white hands adorned with green rubber transplant awareness bracelets. A young child captured mid-stride as he races down a track. “You can give Hope, Compassion, Life – as an organ and tissue donor,” reads the mute text.

A lone black man looking longingly into the distance symbolizes the “thousands waiting for a gift that only you can give.” The music crescendos, the sunrise melts to a royal purple glow, and a worshipping congregation stands in solidarity. They hold aloft a multitude of candles that entreat both God and the viewer. The text commands us, repeatedly, in a variety of font sizes, to Pray. We are shown two toddlers, presumably dying. Then the text orders us to Celebrate. A parade of happy recipients passes by. Kathy and Dillon tell us about their “gratefulness” for the “blessing” they have received. Jackie asks, in a paraphrase of the earlier biblical quotations, “Would you give to another, freely, to save their life?” Finally, the text directs us to Honour those who give the gift of life and a quick series of memorial vignettes flashes by, including Londell who “always said ‘I want to be here when I’m gone.’”

“What does it mean to give?” the text asks in summation. Selfless, honour, love – fuzzy and faint the words circulate around the screen. “What does it mean to give…thanks?” Give thanks to Him and praise his name. Psalm 100 makes the concluding statement. The screen switches to the logos of the sponsor and their affiliates and the tag: Give thanks. Give Life.

Organ transplant troubles traditional conceptions of death (of which Christianity has long been the guardian in North America) and muddies Christian convictions about
embraced souls created in God’s image and resurrected in the fullness of time.\textsuperscript{18} The Biblical references in the One Legacy video seek to assuage these concerns and affix Christian endorsement to this new social and technological practice. This is not particularly unusual. Scriptural treatments are frequently applied to foreign customs or cultural innovations seeking religious sanction. But the One Legacy video also asserts that donating organs is a religious act. These are not the same thing. To say, for instance, that foregoing circumcision, eating meat on Fridays, using birth control, and marrying the same sex are (increasingly) permissible acts for Christians is not to say that these acts have inherent religious meaning or value. Transplant advocacy does more than ask permission. In its allegory of organ donors who love like Christ, its testimonials from religiously ‘moved’ recipients, its juxtaposition of religious worship and transplant ‘blessings’, the One Legacy video argues for the equation of organ donation and Christian truth. According to Bryan Stewart, One Legacy’s Vice-President of Communications, the video was intended as a “tool” to “amplify the message” that organ transplant coincides with “spiritual sentiments” (personal communication, 2008, Feb. 22).

In October 2006, the video quit the confines of California’s Christian congregations. It travelled to the national meeting of American IOPAs where its screening produced a charged response. The CEO (according to Stewart “not normally an emotional guy”) became quite choked up. Presumably, other procurement professionals were similarly stirred. Many of them ordered copies of the video to enhance outreach efforts, arranging with the producer to have the video re-tagged with their agency’s logo and sponsorship. Now in the hands of professional and amateur transplant advocates across America, it subsequently aired in a variety of public spaces,
some Christian, some not. I discovered the video on YouTube. It sported a “Life Connection of Ohio” tag, was posted by someone from El Paso, Texas and linked to 28 other transplant videos (primarily promotional endorsements from organ procurement organizations, but also broadcast news footage, recipient video journals and donor eulogies).

One Legacy was singularly responsible for the conception of this video. A communications agency produced the visuals and music, but the procurement organization selected the scriptural passages and created the storyboards. They sought no pastoral guidance. When I asked how he knew what Christian referents to feature, Stewart replied: “You see them. They’re well circulated.”

Indeed they are. The circulation of “spiritual sentiments” arguably begins with the faith outreach efforts of transplant advocates, but Christian allusions and allegories have been implicitly cited and amorphously expanded through so much promotional material that they are almost palpable. One Legacy would not use this sort of explicitly Christian video in general market advertising. For that, Stewart explained, they follow the guidelines of the national campaign, Empowering Testimonials, which features the stories of grateful, rescued recipients in an effort to get listeners/viewers to “connect to the issue.” When I suggested that Christian notions of helping others are perhaps embedded in the Empowering Testimonial ads, he immediately concurred: “Oh yes, the Good Samaritan theme.”

Muted and fragmented, the halo of Christian equivalency nevertheless lights much transplant advocacy. Canada’s federal campaigns of 2001 and 2002 featured a 30 second television spot with candles on a cake that blow out and then spontaneously re-
light. The spot suggests the “re-birth” of the recipient. It also references (implicitly) the extended donor’s life, the desire to “be here when I’m gone.” The television ad built on an earlier Kidney Foundation poster campaign that featured a single candle (sans cake) and copy that read, “Make sure you get your wish. Tell your family you want to be an organ donor.” In the hazy aura of these ‘general market’ candles one can sense the candles that flicker through faith outreach efforts, and the centuries of candle use in the Christian tradition -- votive candles, altar candles, Paschal candles, processional candles, holiday candles, memorial candles -- their light symbolizing the light of God, or more specifically, Jesus, “the light of the world.” There are no scriptural endorsements or prayer directives in these ads, but there is a reverent glow.

The lighting of candles on a cake makes invisible reference to the giving of gifts. “The Gift of Life” is the most ubiquitous tag line in transplant advocacy. It headlines newspaper reports, concludes advertising spots, names OPOs, and pins itself on a host of lapels. In 1999 the Toronto Sun published an 8 part series dedicated to telling transplant stories and encouraging organ donation. Entitled ‘The Gift of Life’, the Sun managed to fill an entire tabloid page with those four words. In Ontario’s 2002 campaign, the newly formed Trillium Gift of Life Network splashed this slogan all over Toronto’s subway stations and transit shelters. Clean white panels featured nothing more than the agency’s logo (the provincial flower, a white trillium, looped with a green ribbon) and five sentences of copy: “Be an organ donor. Sign your donor card. Tell your family your wishes. Give the Gift of Life. Lives depend on you.”

Perhaps little visual embellishment was needed, the resonance of the phrase being enough to evoke a number of powerful Christian motifs: God’s gift of life to humankind,
the gifts of the Holy Spirit that strengthen the life of the Church, Jesus’ life “freely given” for the life-everlasting of the faithful, and the gift of spiritual life for those who would imitate Christ’s love. The One Legacy video elaborates these tenets. The Gift of Life slogan condenses them, blankets them under hallowed sentiment. However, William LaFleur (2002) argues that such a phrase, even when scratched only lightly, “even when it is passed off as secular, reveals close to its surface the notion of agape” (640).

The penultimate biblical exemplar of agapic love is the parable of the Good Samaritan. “Who is my neighbour?” an expert in the law challenges Jesus, when Jesus tells him that the ancient precepts -- to love the Lord your God with all your heart and soul and strength and mind, and to love your neighbour as yourself – are the keys to eternal life. In reply, Jesus tells the story of a man waylaid and beaten by robbers as he travels the road from Jerusalem to Jericho. One after another a priest and a Levite (members of the elite religious classes in Jesus’ day) pass by their fellow Jew. But a Samaritan, a foreigner, a member of a northern apostate sect despised and scorned by mainstream Jews, takes pity on the man. He dresses his wounds, transports him to an inn in Jericho, leaves money for his continued care and promises to return and reimburse the innkeeper for any additional expenses. The stranger turns out to be the most neighbourly of all, and the compassion that crosses all social, ethnic and theological borders the most emblematic of Christian love.

Transplant advocacy frequently references the deep satisfaction to be gained from aiding a stranger. In 2004 the British Columbia Transplant Society designed a series of posters for an outdoor advertising campaign. The top half of the poster featured an
enigmatic proclamation set against a vivid orange background: “GIVE SOMETHING VALUABLE TO A TOTAL STRANGER.” The bottom half of the poster reverted to a more sedate font size and a plain white background to explain “the gift of life” and to persuade British Columbians to enrol in the provincial donor registry.

Ontarians were pitched a similar message in the 2001 Report to Ontario Taxpayers. The political equivalent of an infomercial, the Report gave a positive and persuasive recap of the government’s accomplishments and agendas and was mailed to every household in Ontario – a compelling example of the elite reach and hegemonic power that substantiates the sale of public goods (Rutherford, 2000). As the province geared up to “double organ donation rates by 2004”, the cover of the Report featured a full-page picture of a grinning toddler climbing on a playground apparatus with the caption “A Total Stranger Saves Seth’s Life”. Inside the report there were several testimonials from recipients and their families. “I pray everyday,” Seth’s father related, “for the family who gave Seth his life back.”

Resting donor appeals on the thrill of aiding a stranger (and a “total” stranger at that) is counter-intuitive without the guiding moral rubric of the parable of the Good Samaritan. While cadaveric organ donation is anonymous in Canada (technically one always donates to a stranger), emotive appeals could just as easily be made to rescue ‘fellow citizens’ or the nameless but familiar acquaintances of your neighbourhood – bakers and bus drivers, etc. Utilitarian appeals might stress our collective obligation to donate organs so that those nearest and dearest to us will be able to benefit from our mutual willingness should they ever be afflicted with organ failure. The call to give something valuable to a total stranger, however, places organ donation squarely in the
shadow of the Good Samaritan. It extends the metaphor of the Gift of Life, it reflects the reverent glow of candles and it honours organ donors by placing them in the company of a figure who has, for centuries, captured the essence of Christian love in his challenge to conventional understandings of neighbours and strangers.

I suspect that transplant advocates don’t consciously set out to sway potential donors with subliminal Christian messages. General market forays echo faith outreach efforts, but always faintly. The promotional efforts of various sponsors to various markets borrow from and build on each other. What is “circulated” are the remnants of a cultural reservoir of Christian symbol and metaphor that stirs an emotional response – it “moves” people or “chokes them up” – without any reliable cognitive theological counterpart. At least it moves some people. There are no studies that explore this aspect of audience response to transplant advocacy. But there are suggestions (in the pronounced willingness of Christians to participate in living anonymous donation and in the reticence of some non-Christian populations to donate organs) that those audiences who can most easily read the Christian sentiments that animate much transplant advocacy are the ones most convinced of the spiritual import of organ transfer. For those who can discern, even intuitively, the parable of the Good Samaritan in the appeal to aid a total stranger or the mystery of Christ’s passion in the solemn petitions to give the Gift of Life, it makes perfect sense that Heaven wants our organs here.

Some might see the marriage of organ transplant and Christian faith as innate. The foundational Christian archetype of Jesus’ willing bodily sacrifice to extend and enlighten human life appears to have such immediate parallels to the act of voluntary and unrewarded organ donation that the chorus of scriptural analogues are therefore natural
and spontaneous. I disagree. Scriptural analogues are constructed and asserted, although
this doesn’t render them false. Organ transplant advocates have the same rhetorical
necessities as any social movement. As Rhys Williams (2000, 2003) points out, social
movements have to legitimize their aims (to both the public and their members) in
cognitive, affective and motivational terms. Williams argues that in North America
religious language, historically and inherently, has a particular ability to make public
political claims. It is democratically available (not bound to ecclesiastical organizations
and clerical hierarchies), spoken by a broad range of political actors (not always
religiously affiliated), widely resonant, affording powerful sanction, and seeking a
potentially universal public. “Considering the wide identification with religion in
American society, and the presumptive legitimacy that religion generally enjoys both
legally and culturally, there is only one other public discourse – ‘rights talk’ – that can
rival religion as a medium for public claims” (Williams, 2003, 178) 22.

Organ donation does have affinities with Christian doctrine, attested to by many
Christian voices. But Christian understandings both parallel and repel transplant
technologies, as many Christians are aware (see Chapter 1). Guided by a logic of
marketing, the transplant lobby has marshalled specific Christian images and narratives to
sell organ donation as a public good. Where those efforts resonate, audiences (including
some Christians, some donors and recipients, and some ‘general market’ members)
circulate and validate the Christian tropes of the promotional literature. They post the
videos on YouTube, they sport the Gift of Life pins and they declare that “Heaven wants
our organs here”. The sacralization swells (losing Christian caveats about organ donation
in the tide) and slips from its moorings, leaving organ transplant floating as a non-sectarian, but vaguely sacramental, public good.\(^{23}\)

It would be remiss to suggest that all transplant advocacy hinges on Christian allegory. It is a significant aspect of the promotional media, but the mantle of celebrity and the accolade of hero are also prominent features of awareness campaigns. They likewise participate in the moral logic that animates transplant advocacy. The transplant lobby enlists ‘stars’ to speak on behalf of organ transplant and heralds those who would donate organs as social champions. Both kinds of luminaries lend their aura to the project of ‘honouring’ this public good.

“Calling it as I see it on Hockey Night in Canada is exciting, but it’s nothing compared to making people more aware of an issue that’s very close to my heart.” So says hockey personality Don Cherry in the 2001 Report to Ontario Taxpayers, where he describes his own family’s encounter with kidney failure and organ donation. The headline tells us that he is speaking “from the heart” this time rather than off the cuff as he is wont. The celebrity pitch is a regular feature of transplant advocacy. Alongside the candle ads, the newspaper supplements and the promotional products, the federal awareness campaign of 2002 also featured 10 and 15-second public service announcements featuring Canada’s illustrious track athlete Donovan Bailey. Public opinion research established the Donovan Bailey spots as the most frequently recalled national ad of the campaign (Envirions Research Group, 2002). More recently, the Trillium Gift of Life Network developed a whole stable of stars for their Celebrity Awareness Campaign. Politicians, media personalities, professional athletes, musical artists, actors, directors, even Roberta Bondar, Canada’s well known astronaut, lend voice
and visage to the cause. Under the banner “I’ve talked to my family about ORGAN DONATION. Have you?”, their large smiling head shots grace a series of black and white posters. These are permanently displayed on the TGLN website and regularly distributed at sporting events, community gatherings and organ donation awareness functions.

Rutherford (2000) demonstrates the extensive use of celebrity endorsements in civic advocacy, particularly in the promotional efforts of charity organizations. “The presence of celebrities not only attracted the eye but carried conviction, or so it was thought. The stars…had acquired a kind of authority as truth-tellers” (122). If the conventional requests for cash donations benefit from celebrities’ notability and believability, how vital such endorsements become for the rather aberrant appeal to divest ourselves of our organs. In addition, celebrities provide useful tie-ins to publicity endeavours.

Something of a cross between advertising and journalism, publicity is news spawned by the promotional efforts of various lobbies. Publicity accounts for a significant and increasing percentage of all news coverage (see discussion Rutherford, 2000, 259). In many ways the cheapest form of advertising, publicity is a mainstay of transplant advocacy. All sponsors—organ procurement organizations, health promotion agencies, medical associations, transplant hospitals and recipient associations—circulate press releases and convene press conferences. Organ procurement agencies (whose marketing efforts have more financial and bureaucratic clout) also produce and issue video news releases to the TV networks.24
The publicity efforts of various sponsors have typically converged on NOTDAW, the April “Awareness” Week. However, Trillium Gift of Life Network, Ontario’s organ procurement organization, has also decided to target publicity around “times of family gathering and gift giving” (Christmas, Valentine’s, Easter, Mother’s Day, Father’s Day and Ontario’s new holiday: Family Day) (see TGLN, News Releases). Not only does this spread media coverage of organ donation across the calendar, it affords associations between the act of donation, Christian holy days, family bonds and rituals of gift giving. Another way to keep organ donation in the news is to entice reporters with the lure of a celebrity story – the drama of Don Cherry’s daughter donating a kidney to his son or the signing of the Toronto Marlies hockey team to the Celebrity Awareness Campaign. Publicity often functions as a “media echo” (Rutherford 2000)), transmitting the rhetorics and postures of advocacy campaigns across a wider mediascape. The moral logic of transplant advertising extends to transplant publicity. Slogans such as the gift of life and the circle of life headline articles. Miraculous recipient testimonials are the backbone of press reports. Television coverage shows celebrities endorsing organ donation at transplant awareness events. Editorials talk about donors (and organ shortages) “living on”. The fate of Kristopher Knowles (and a legion of children like him) plays out on the evening news.

Roberta Bondar, Donovan Bailey and Don Cherry are not only celebrities – they are Canadian ‘heroes.’ They embody some aspect of Canadian identity, represent the heights of Canadian achievement and are presented to Canadians, especially Canadian school children, as role models for personal achievement and public commitment. (Don Cherry -- “a hero to some, a bigot to others” -- is too controversial to be touted as a youth
role model. He has, however, become synonymous in Canada with a certain kind of folk identity. Their endorsement of organ donation suggests that would-be donors might similarly be regarded as Canadian heroes: outstanding individuals dedicated to the well-being of their fellow citizens and resplendent with the qualities that embody this nation and make it flourish. This suggestion is made explicit in a great deal of transplant advocacy.

“Sir, if any of my circuits or gears would help, I’d gladly donate them,” says Star Wars character C-3P0 to his battered compatriot R2-D2 on a placard produced by Canada’s association of transplant professionals (CAT), the Kidney Foundation and their corporate sponsor, The Mutual Group insurance company. “You can give the gift of life…and be a hero right here in this galaxy,” the placard explains. This promotional appeal is rather unusual in its metaphorical association of organs, circuits and gears, its light humour, and its presentation of galactic heroes rather than national ones. Transplant advocacy is usually rather staid, its heroes portrayed as social beacons, and its organs almost always somatic, if generally invisible. More typical is a poster developed by the transplant program of the London Health Sciences Centre in 2004 and distributed throughout southern Ontario. An organ recipient, a small child, is seated with a firefighter, a paramedic and a police officer. An ambulance is parked in the background. All four hold organ donor cards. The text reads: “A different kind of hero…Consider organ donation.” Smaller print briefly tells of Sarah’s liver, bowel, stomach and pancreas transplants and closes with the caption: “Be a hero too and sign a donor card.” Most advocacy efforts honour the organ donor as social hero (like the emergency personnel), not outer-space hero.
The idea of cultivating social heroes is central to the Trillium Gift of Life Network’s efforts to form “community partnerships” through their Champions for the Gift of Life program. TGLN develops affiliations with various social groups – regional police forces, church councils, charitable organizations and professional bodies. They distribute their literature and promotional items to the membership and stage a wide range of “media activities” (photo opportunities, media-tized rituals) designed to garner “broad based and positive coverage of organ and tissue donation across the province” (TGLN Annual Report, 2004-5, p15). The industrious, the charitable, the religious and the guardians of society all become “champions” by virtue of their willingness to support organ donation. These associations are performed repeatedly in the news media reports. Soaked in this marinade, organ donors become industrious, charitable, spiritual and courageous social heroes in their own right.

Heroes perform on a wide cultural stage, but most expressly for the young. The idea that youth need role models and mentors for positive development is one aspect of this. However, consumer marketers have long known the importance of capturing the youth market to ensure enduring brand loyalty. Social marketing is no different. It is easier to sell a good habit before a bad habit is in place, and public goods sold to the young will continue to pay dividends for many years to come. These dividends include not only putatively healthier bodies, but also a corpus of young citizens well versed in the consumption of public goods and the mode of governance this promotes. Organ donation is one of a myriad of public goods marketed aggressively and specifically to children and adolescents.26
A particularly striking example from the U.S. is the Creative Challenge of the Donor Awareness Council, a Denver, Colorado non-profit organization devoted to providing public education about donation. In operation for well over a decade, the Creative Challenge features a series of poster contests for grade 6 – 12 students across Colorado and Wyoming. Students are asked to create an image that captures the essence of organ donation. The winning posters are displayed at a gala event; one of these is chosen as the Council’s T-shirt insignia for the upcoming year. The Creative Challenge draws close to a thousand entries annually as many teachers incorporate the artistic rendering of organ donation into their classroom curriculum. Youth are an important audience in Canada too, as the Kris’ Wish campaign amply demonstrates. The TGLN Annual Report (2004-5) remarks that “targeting youth of all backgrounds is an important strategy” (15) and to this end they regularly advocate to post-secondary student associations and participate in frosh week activities on university and college campuses.

In its moral logic of honouring those who have, and those who would, donate organs (the Christ-like Samaritans of our age, the minor celebrities and civic heroes of our communities), transplant advocacy not only sells this public good to the general market, it scripts “a set of ‘feeling rules’ for the experience of organ donation…it presents the ideal experience, what one ought to feel in these circumstances” (Healy, 2004, 309). Healy argues both transplant advocates trying to rationalize procurement and donor kin trying to make their decision meaningful engage in “cultural work” that dominates the public account of organ donation. A review of donor kin narratives published in book-length personal memoirs, in journalistic accounts and in transplant advocacy materials reveals “a template for those who might be put in the same situation”,

an emotional roadmap charting both tremendous suffering and a route to feelings that are positive and life-affirming (Healy, 2002, 315). The template positions organ donation as a way for the bereaved to come to terms with the (often sudden or violent) death of a loved one. The template also posits organ donation as a moral act with religious significance, and a way to guarantee one’s (positive) memory after death, a kind of immortality evoked by the various ways organ donors are said to “live on” – in memorials such as donor quilts and cenotaphs, in the public proliferation of their story, in the infrequent (but oft heralded) occasions where donor families develop ‘kinship ties’ with recipients and their families, and, most evocatively, in the organs that animate the recipient.

Healy’s review of the literature (1980–1999) finds that alternatives to this dominant script become less and less available as the cultural work of advocates and donor families builds. Drawing on Robert Wuthnow’s research on narratives of volunteering, Healy argues these highly personalized stories about the motivation to donate organs function as models of and resources for subjective selves, rather than philosophical appeals for altruism or value-laden arguments for pragmatism. They assert a particular subjectivity. The narrative is formulaic and full of elisions, but is made to speak (in the recounting of historical details, character traits and poignant emotions) to the unique individuality of both donor and donor kin.

This proclivity to build personal identity through the prescribed public scripts of organ donation suggests there is more than one kind of ideological thrust to transplant advocacy. Drawing on a traditional Marxist frame, Nancy Scheper-Hughes (2000) and Lesley Sharp (2001) have linked transplant advocacy to “commodity fetishism” whereby
the fetishized organ masks the true value of organs, the realities of production, and the person of the donor (see extended discussion in Chapter 2). Rutherford (2000) draws on Gramsci’s discussion of hegemony -- ideological production by power that is routine, institutionalized, organized, generally accepted, legitimate -- to explain the selling of public goods (of which organ donation is but one). But Healy’s account is more reminiscent of an Althusserian notion of ideology that, according to Terry Eagleton (1991), posed a sort of ‘breakthrough’ in modern Marxist thought:

An imaginary self transcends – in the ideological realm – its true state of diffuseness or decentrement and finds a consolingly coherent image of itself reflected back in the ‘mirror’ of a dominant ideological discourse. Through ideology, Althusser remarks, society ‘interpellates’ or ‘hails’ us, appears to single us out as uniquely valuable and address us by name. Ideology brings us into being as individual subjects. (Eagleton, 1991, 142)

Ideology is now not just a distortion or false reflection, screen between ourselves and reality, automatic effect of commodity production. It is an indispensable medium for the production of human subjects. (Eagleton, 1991, 150)

In Althusser’s sense of ideology there is a tension between the apparent agency of the self to articulate its deepest dimensions and proclivities and the ideological apparatus, the material practices and institutions, that makes such dimensions and proclivities apparent. The twinning of transplant advocacy and donor narratives is emblematic of this tension.

Organ donation emerges as “heroic” in the public accounts not only because of the accolades bestowed by transplant advocacy, but because live donors and the families of deceased donors, like celebrities more generally, are a kind of “truth-teller”. In their personal (yet public) narratives they expose the ‘truth’ about the self, its journey into great emotional depths, its memories, sensations and sentiments, and – especially -- its bonds to other selves. Charles Taylor (2004) argues persuasively that the modern social imaginary (our implicit and normative grasp of social space), rests on a vision of
subjective and free individuals meant to collaborate in peace to their mutual benefit. The private self we now imagine ourselves to be was born in the re-ordering and invention of public spaces in the modern era. “We tend to read the march of this new principle of order, and its displacing of traditional modes of complementarity, as the rise of ‘individualism’ at the expense of ‘community’” (17). But modern individualism is not a rejection of communal ties, Taylor asserts. “Indeed, this revolution of personal independence heightened the sense of belonging to the wider society” (150). The narrow bonds of kinship and the great chains of dependency erode, but are replaced by the fealties of a horizontal society of equals, produced in the metatopical spaces of the nation, the press, and the public sphere. “Modern individualism…doesn’t mean ceasing to belong at all…but imagining oneself as belonging to ever wider and more impersonal entities: the state, the movement, the community of mankind” (160).

Organ procurement can be rationalized and donor decisions made meaningful by linking to this modern sense of moral order: organs are the gifts of free individuals, of mutual benefit to donors and recipients, given out of the very depths of the subjective self, but nonetheless indicative of the breadth of the social net that enmeshes us. Organ donors become heroes when the “cultural work” of advocates and participants reveals the synchronicity between this practice and our intuitive sense “of how things usually go, interwoven with the idea of how they ought to go” (Taylor, 2004, 24). Conversely, transplant expressions, experiences or associations out of sync with our modern social imaginary threaten to render the practice of transplant immoral or incoherent.
Contract players, free agents and morally muscular missionaries

Organ recipients are also active in the “cultural work” of transplant. Their testimonials, perhaps even more plentiful than those of organ donors, are likewise seen as a form of “truth-telling” about our modern social selves. This is why they are felt to be “empowering” – as the US National Campaign refers to them. But recipients are not heroes. That part is scripted for the organ donor. Watching the passion play of organ donation unfold in the media around us, we know that the organ donor is the Good Samaritan. They are analogous to Christ in their willingness to make the stranger’s welfare their deep concern. But our recognition of the play extends to all the characters. The religious identity of the organ recipient is equally familiar to us: they are the needy penitents longingly awaiting a miraculous touch.

Compared to the saintly donor, the recipient’s identity has more range. The public roles and private subjectivities available to the recipient are considerably more ambiguous. Penitents simultaneously embody the relief of deliverance, the countenance of contrition and the stigma of sin. These aspects of the penitential character are what mark representations of the organ recipient in popular media. Recipients are alternately portrayed as humbly waiting, reverently thankful, and morally suspect.

Depictions of the organ recipient have a ‘before’ and ‘after’ character. Awaiting transplant, recipients are routinely portrayed as passive but hopeful. This is underscored by advocacy slogans such as “we live because of you” (Kidney Kommunicator, Fall 2003) and by media narratives that allow would-be recipients no other posture than that of mute waiting: “Every day 17 people die while waiting for the organ donations… These men, women and children spent their final days ever hopeful that the gift that would bring
them a second chance at life would come” (Golden State Donor Services, 2002). The helplessness of their condition is routinely highlighted. “Kim, once too weak to push the buttons on a telephone. Neil, who could barely find the breath to whisper. And Sandra with the sickly yellow eyes, who struggled to comb her hair” – such is the introduction to the lives of recipients prior to receiving their transplant in a Toronto Star review of the transplant dragonboat team (Gamester, 2000). The article fails to mention the dialysis patients who also paddle with the team.

But the article does not fail to mention the hush that falls over the group in the midst of their fun: quiet times devoted to thoughts of their donors and donor families who gave them this second chance at life (Gamester, 2000). Media coverage of those who have received a transplant portray recipients as devoutly grateful – praying for donor families, acknowledging their donor in moments of silence, participating in organ donor commemoration.

However, the broader media discourse harbours a suspicion that the sinful nature of the organ recipient, part of the penitent’s very character, may prove more potent than either reverence or faithfulness. Equally as eye-catching as the Toronto Sun’s Gift of Life series was the Globe and Mail’s front page ‘special investigation’ into black market organs and transplant tourists – the recipients who travel abroad to illegally purchase kidneys (Priest & Oziewicz, 2001). “Dr. Horror” was the nickname the press gave to Amit Kumar, an Indian doctor residing in Toronto and charged with orchestrating a large and nefarious traffic in ill-gotten third world organs for his first world customers (Wattie 2008). Transplants deemed unethical, such as the case of Murray Menkes, are given considerable media attention (see for example, Priest 2002). The wealthy Menkes was
apparently offered a kidney from his long-time housekeeper. Yet several Toronto hospitals refused to go forward with the transplant citing ethical concerns about the hierarchical relationship between employer and employee. Menkes subsequently had the transplant performed at the Mayo Clinic and attempted (unsuccessfully) to bill the provincial health care plan for the cost. Crime, criminal records and receipt of an organ are frequently linked. One Toronto editorial argued recipients feel entitled to other people’s organs (Blizzard, 2000). Popular movies, science fiction novels, television crime dramas and urban myths revel in tales of organ snatching that generally benefit rich and/or unscrupulous recipients.

The civic sin of scarcity and the sacramental counterpoint used to sell this public good have provoked criticism that, in part, informs this negative press. Scholars (Jorelman 1995, Sharp 2001) have questioned the “reek of virtue” emanating from transplant advocacy and their critique is occasionally echoed by media commentators: “A gift is something given willingly. The family would far rather have its loved one back” (Blizzard, 2000, 16). Anthropologists have also been frustrated by the advocacy emphasis on de-contextualized, constantly promulgated, and evermore widely defined lists of candidates waiting for organs (Scheper-Hughes, 2000, Sharp 2001). In both the ICUs of the first world and the slums of the third world, they argue, these “artificial scarcities” (Scheper-Hughes, 2000) foreground the needs of the dying recipient and cast the body of the donor in shadow. Some of these scholars have initiated a watchdog agency, Organ Watch, to monitor and report on transplant abuses. Organ Watch founder, anthropologist Nancy Scheper-Hughes, was oft quoted in the Globe & Mail article reporting on overseas kidney sales (Priest & Oziewicz 2001). The highly charged moral
language of this counter-propaganda was pronounced: would-be recipients were “clamouring” and “grabbing” for healthy kidneys as they embarked on their “surgical holidays” to acquire this “commodity” on the “black market.”

The small cadre of elite voices that counter transplant’s official public script have neither the organizational strength, gate-keeper affiliations nor sophisticated methods of surveillance and spectacle to compete with the transplant lobby in the production of civic advocacy. Nor can they be held responsible for the proliferation of imagined scenarios of organ sales and organ snatching (most of it set in the first world) that flicker on our theatre and TV screens, advance across the virtual lands of the Internet and live in the pages of tabloids and serious novels alike. Some have argued these popular narratives of transplant carnage represent deep seated fears about transplantation that reside “below the level of full consciousness” (Fiedler, 1996, 58), “breathing new life into the psychic legacy of body snatching” (Youngner, 1996, 41), connecting to “the collective horror Americans share for the utilitarian use of human bodies” (Sharp, 2006, 12). But quite possibly it is neither unconscious resistance to the technology of transplant, nor the stoking of conscious resistance to transplant abuses that sustains these dark and dystopian fictions. Quite possibly it is the very success of transplant’s official rhetoric of scarcity and needless death that makes the stolen organ so prominent a part of popular North American culture.

The authors of a website devoted to research on urban legends suggest the following rationale for the widespread 1990s urban tale (frequently translated into television crime dramas and Hollywood movies) of a weary business traveller who, after
drinks with a stranger in the hotel bar, awakes in a bathtub full of ice minus one of his kidneys, which has been surgically removed:

The best explanation I can offer as to why this bit of scarelore has gained, and kept, its popularity, has to do with the growing familiarity of the general population with organ transplants. As these procedures have become more a part of the world we live in, so has awareness of the problems associated to them. The stark reality is that there are more people in need of transplantable organs than there are organs to go around. Knowing that, it’s reasonable to believe wild stories of kidneys being hijacked from the unwary. Standing in the shoes of someone desperate for this procedure, wouldn’t you be willing to pay just about anything to secure what you needed to keep on living? (my italics) (“You’ve got to be Kidneying”, n.d.)

“It is the intention and goal of TGLN,” states a 2006 press briefing, “to ensure that all Ontarians know how large the organ and tissue waiting list is at all times…” (TGLN Backgrounder, 2006). It is both plausible and ironic that the more transplant advocates succeed in making North Americans familiar with the size of the waiting list, the more credible the desperation of recipients becomes, and the more pervasive the organ stealing rumours of the affluent first world. 30

Organ procurement personnel view the pop culture portrayal of greedy, desperate or powerful recipients working with rogue doctors to obtain organs illicitly as one of the biggest media-relations challenges they face (Carrie Hoto, Media Relations, TGLN, personal communication April 12, 2008). Considerable effort goes into containing the threats these narratives pose to the official transplant roles of mute, passive, grateful recipients and their willing benefactors. In an effort to curtail deviations from the official script, American OPOs have joined organizations that work to favourably showcase social causes in American television, much as consumer advertisers try to reach audiences through product placement in movies. In a report called “Working with Hollywood to Deliver Your Message to Millions”, authors Karen Brailsford and Andy
Goodman (2006) recount how Bryan Stewart of One Legacy influenced the final script of a *CSI: New York* episode about a liver stolen in transit, convincing the writer to make the villain a doctor rather than a wealthy recipient, as originally intended. Stewart then launched a well-timed press volley designed to “offer the reality behind the drama”.

Sometimes the advertising efforts of OPOs counter the seamy transplant fictions more subtly, as in the 2006 BC Transplant Society television commercial entitled “Cooler Ad”. In this spot, the camera follows the ominous cooler (whose presence in the fictional dramas always signals nefarious business) as it is transported from a medical centre. Only the container and the rapid footsteps of the man carrying it can be seen, shrouding the cooler’s journey in suspense. The voice-over speaks about the critical shortage of organs and the hundreds dying. The cooler doesn’t arrive at a hospital, but detours further and further from urban, professional settings until it comes to rest on a park bench. We see the torso of a woman who has been anxiously waiting. Hands reach for the lid. It swings open.

But the cooler doesn’t reveal the expected organ on ice. The shady black market transaction between a corrupt medical official and a desperate recipient fails to transpire. The hurried journey and shadowy rendez-vous turns out to be nothing more than lunch in the park. “Sorry, I’m late,” says the man as he hands the woman a sandwich from the cooler. “Please register to be an organ donor today and live on,” concludes the voice.

The “Cooler Ad” spot is clever in its ability to transpose the images of the fictional transplant dramas, but ultimately one wonders about the ability of OPOs to stem the tide of popular portrayals of desperate recipients and their illicit pursuit of an organ. The containment strategies become more ingenious, but simultaneously OPOs become
more committed to the scary sell. In 2005, TGLN’s radio and outdoor advertising
campaigns featured “a change in message from ‘Thank you for saving my life’ to the
more urgent message of “Every three days someone dies waiting for an organ” (TGLN
2005-2006 Annual Report, 7). Such a shift may produce a perception of desperation as
well as an awareness of urgency, making the tales of organ snatching and organ sales all
the more compelling, to both producers and viewers. In this sense, successful advocacy
may contain the seeds of its own demise.

Nor can the rearguard actions entirely erase the popular fear that recipients are
dangerous and deviant. A wary member of her listening public once accosted recipient
Kate Green, whose transplant story is well known in local circles due to her radio show,
in a grocery store parking lot. “So how is it,” the woman asked suspiciously, “that you
were lucky enough to get three transplants?” “How is it I was ‘lucky’ enough to need
three transplants?” Kate complained to me bitterly.

It is not only the sensational stories and the scary sell that present recipients as
shady characters. Transplant advocacy is not an isolated pitch, but part of a rising tide of
civic advocacy, much of it dedicated to selling public health measures and unselling
‘risky’ behaviours. Health advocates anxious to rid society of “public bads” have very
effectively tied organ failure to issues of lifestyle. Smoking, heart failure and lung
damage; drug use, hepatitis C and liver failure; drinking and cirrhosis of the liver – health
advocacy regularly advances these correlations and in so doing conspires to make the
adult organ recipient morally suspect.31

Well, I spent 30 years as a police officer in Toronto and I’d just retired….I’d been offered
a job out in Scarborough as a client manager of a factory out there. So I kind of left a
little early to take that position. So just after retiring I thought, ‘I might as well go for,
you know, the annual check up (that hadn’t been done for…the old 10,000 mile check
up!) So he did the blood work, etc. And then he said, “Come on back. Your blood platelet levels are a little out of kilter. We’ll have to find out why.” So more blood and more checks. And then I had to see a gastroenterologist.

And then I was told that I had cirrhosis of the liver.

“I don’t drink!” Duncan exclaimed. “You know, social drinker, not like a hard drinker,” he qualified. “I was told: you can be a teetotaller and have cirrhosis of the liver. Because it’s scarring of the tissues, and there’s a weakness…”

But despite the medical assurance that there need be no correlation between alcohol consumption and cirrhosis of the liver, Duncan is still captured by the popular associations.

I mentioned earlier that I did my family tree. I traced it back about probably six or seven generations. Mostly dock workers. So there’s been a lot of hard, hard drinking over the generations. And I think there’s a weakness that’s just been passed down to me. So, you know, I was a social drinker, but that weakness has caused some very serious damage to my liver.

Within seven months of the diagnosis, Duncan had to quit his job. He described the jaundice, hair loss, liver spots and unfathomable weight loss, 65 pounds from his trim frame. Family, friends and former members of his unit are shocked by his appearance.

I remember after I retired, about six or seven months later, they had the big retirement ‘do’ for my division, because there was about 15 guys that retired. So they hadn’t seen me for about seven months. And I walked into that room and it was like: OH!

I looked like a cancer patient. Cause even my clothing—none of my clothing fit me. The necks of my shirts were down here. And I was yellow. And my cheeks were red. Eyes were in. Just looked like a cancer patient in advanced stage. Um, skull… So there was a lot of shock when they saw me.

The fatigue and depression mounted. “A lot of days I was tired 20 hours a day.”

His wife left her employment in order to care for him. And the family were tested to see if there was a suitable live donor. His son Graham was a match and underwent the requisite psychological and physical testing. The transplant took place in June. “They
told me after the surgery that I would have been dead by Christmas. If it had not been for Graham. But I know, I would’ve been dead in two months.”

The risks of living liver donation are not negligible. The right lobe, about sixty percent of the adult donor’s liver, is transplanted to the recipient; the remaining forty percent is left to regenerate. Complications occur in approximately 30% of all donations (major complications in approximately 3.5% of donations), the most common problem being bile leaks (Patel et al, 2007). The situation was very taxing on remaining family members. “My mom was nervous, but my sister broke down,” Graham related. “It must have been very tough those hours we were in there. I wouldn’t have liked to have been there.”

I also wondered how Graham’s young peers reacted to the magnitude of his decision and the risks he was taking.

Some people have said “I don’t approve; I don’t agree with it or believe in it because it is playing God a little bit.” Not many, but a few. It’s a different way of thinking about it. Again, I respect that. I see where the line of thinking comes from…. But every case is different. If my dad had been a raging alcoholic, I’m pretty sure I still would’ve done this, but it’d really be different. You know. If he’d inflicted, if he’d done this to himself, caused this – it would’ve been a different situation. This just happened.

AM: funny that tag cirrhosis of the liver, what that implies to people automatically

Yes! Because whenever I’ve had to tell people what he has, you have to say: “He’s not an alcoholic, never was.” I feel obligated to say that. My sister’s gone through the same thing….

I’ve never drank that much. I’ll go out once in a while, but I just don’t have it in me to drink…. My chances [of getting the disease] will be a lot less since I barely drink at all. Special occasions really.

“And I’ll never drink again!” Duncan interjected.

So powerful are the associations of alcoholism and cirrhosis of the liver that this family wrestles with them publicly and privately, despite the alternate disease aetiology
doctors have extended. Transplant advocates speak alongside a diverse array of health promoters. This varied litany of public goods and social risks means that transplant officials are repeatedly called to respond to the public suspicion that the ‘undeserving’ — smokers, drinkers, drug users -- might be the ones in need of organs. Duncan’s transplant sits in the shadow of Mickey Mantle’s liver, the details of Mantle’s 43 years of alcoholism, suspected queue jumping and “wasted organ” (Mantle died three months after the transplant) reported in countless press stories (see Munson 2002, Harrell 1999). All of these factors make the public recounting of Duncan’s story — at the Kris’ Wish assembly and in various Toronto newspapers – more than a celebratory tale. It is also a defensive manoeuvre. The broader tenets of health advocacy (whereby disease is correlated to risky social behaviours and poor lifestyle choices) are an added inducement for transplant recipients to lend their voice to the affirmative refrains of transplant advocacy.

Examining the prolific use of children in advocacy advertising, Rutherford (2000) finds a general suspicion of adult victims, of which the morally suspect adult organ recipient is an extension. The dependent adult can carry a stigma, Rutherford argues, their dilemmas potentially self-induced, their dependency a drain on social resources. “But the young boy or girl remains a generic icon of hope and innocence in the affluent world, an image less likely to polarize or upset the watching citizens” (2000, 132). The suffering child is a staple of charitable advertising generally, and transplant advertising specifically, because they carry none of these moral ambiguities. Children peer out from the posters, prevail in photo ops, and parade through the transplant publicity. When George Marcello passed the Torch of Life to young Kristopher Knowles it was precisely
this innocence that was sought. “George,” an associate whispered to me, “had a bit of a wayward past.”

In addition to the image of the innocent child, transplant advocacy has heavily relied on recipient testimonials to counter the portrayals of recipients as morally ambiguous and organ transplant as abuse ridden. Recipients have been (largely) willing partners in this endeavour. Many tell their stories in the press, on public platforms, in patient newsletters, on government panels, to other recipients and to strangers they meet on the bus or in the coffee shop (the last is especially true for those who elect to wear the popular promotional button, “Ask me about my transplant”). In many ways, the desires of transplant officials and recipient activists intersect – both are troubled by the popular trope of the suspect recipient, both care deeply for those on waiting lists (the raison d’être of transplant officials, the social milieu from which recipients come), both have experienced the generosity of grieving families who agree to donate and for all of these reasons both are concerned that the technology of transplant be seen as legitimate.

However, the desires of transplant officials and transplant recipients are not therefore identical. The mute, passive and grateful persona afforded recipients in official transplant scripts – while highly preferable to dark characters promulgated in the pop culture dramas – does not always accord with the subjectivities recipients crave, or the health strategies they see as most effective. Because testimonials are “personal” stories, they can sometimes be put to more individual uses. Recipients who publicize their transplant stories can be contract players, free agents, or morally muscular missionaries.

Most are contract players. The vast majority of recipient testimony is heavily managed. Through a process of winnowing and massaging recipient testimony, the
marketing machinery of OPOs, transplant centres, health organizations and professional medical bodies efficiently render these narratives into palatable and consistent public forms. Most transplant advocacy organizations maintain a speakers’ bureau, selecting narratives that conform to a storyline of conversion and speakers that afford a suitably sanctified dramatis personae. These select narratives are the well from which press releases, poster stories, website chronicles and media events are generated. Recipients chosen to speak at formal advocacy events, such as the annual TGLN Celebration of Life memorial service for donor families, submit their speeches to organizers prior to the event (personal communication, Scott Skinner, TGLN). Letters to donor families are likewise vetted (see Chapter 4).

However, it must be remembered that much recipient testimony is self-edited. Recipients have had a long education (much longer than donor families) in the conventions of narrating their transplant story. As patients in end-stage organ failure, they (particularly dialysis patients) are the reading public for a wide variety of communiqués published by various health organizations (the Kidney Foundation, Heart & Stoke Foundation, Cystic Fibrosis Foundation, Lung Association). As recipients, they receive newsletters, bulletins and circulars produced by their respective transplant centres.

These patient communiqués reproduce the language, metaphors and narratives of the advocacy literature. Narratives with headlines such as “A Family Gift of Life”, “A Precious Gift of Love”, “The Pride and Joy of Donation” recount the familiar trajectory of selfless donors, successful recipient conversions and enduring gratitude and bonds. Patients are encouraged to give back in the form of volunteerism and testimonials.
Recipients who are able to insert their story into the mainstream press are congratulated. Reports on the foundation’s advocacy efforts keep recipients in the ‘know’ regarding central metaphors of donation and transplant. Sales of transplant merchandise (T-shirts and pins) retain them as promotional sales staff. Written specifically for recipients (potential and realized), by organizations they belong to, for the purpose of guidance and advice, these publications are particularly conducive to scripting a set of ‘feeling rules’ for the experience of receiving a transplant, much as Healy (2004) argues various kinds of cultural work articulate a template for the experience of donation.

‘Contracted’ recipient testimonials, the kind found in advocacy sponsored by variously affiliated social elites (medical, government and non-profit personnel), are closely related to, but nevertheless distinct from, the testimonials recipients insert directly into the mediascape in advocacy of their own making. The Canadian Transplant Association (CTA) is a recipient organization dedicated to promoting both organ donation and the health of its members through Olympic style Transplant Games and activities such as dragon boating. The passionate play of the CTA inculcates an identity for recipients that is active rather than passive, grateful but also generous, and morally muscular instead of morally suspect. CTA athletics borrow liberally from the persona of the missionary, frequently linked in the 19th century to modern medicine and the medical miracle. As transplant missionaries CTA members proselytize, regularly accepting speaking engagements and frequently working as peer support counsellors in transplant centres. However, like many missionaries they are primarily defined by their ‘works’, in this case their athletic exploits. If the ‘Gift of Life’ metaphor inserts the penitential recipient into a Passion play of organs, the CTA motto – ‘Organ Donation Works’ –
sends forth an energetic recipient with a mission. In their dragon boat races, swim
competitions and track meets, CTA members are to be living testimony to the
transformative power of organ transplant.

Such testimony does not negate gratitude to the donor. “Transplant athletics
send…a message of thanks to donors and donor families for their gift of life,” states the
organization’s promotional materials, and their athletic events generally feature a
commemorative ritual. However, CTA missionaries believe gratitude should not remain
passive and penitential, but be transformed into active works. The song chosen to open
the World Transplant Games in Vancouver captures this belief:

All I can do
All I can do for you now
Is make the very best of my life.

Making the best of one’s life is not to be a solipsistic concern. “The CTA
provides an outlet for one who has received a new life to give something back to the
community”. Giving back to the community can take several forms. As missionaries
they have the ultimate and explicit goal of conversion – in this case, getting people to
sign their donor cards. But missionary work extends beyond winning converts. CTA
members are to bring hope to the unfortunate and model faith in action; “Transplant
athletics”, say the CTA literature, “send a message of hope to the thousands of patients
on waiting lists…and motivate transplant recipients to maintain a healthy lifestyle.”

While organ donation remains a sacramental act in the constructions of the CTA,
the role of transplant missionary elevates recipients above the status of penitents, closer
to the sacred realm where donors reside. “The Future is Yours to Give”, states one CTA
informational brochure. But this slogan, particularly in this context, is ambiguous: those
who donate organs, those who sign their donor cards, and those who convince others to sign their donor cards might all be instrumental in delivering futures. The relay race, the climatic finish of athletic competition at the 2002 Canadian Transplant Games, likewise erased hierarchical bounds normally drawn between recipient and donor. The relay teams featured a recipient, a medical person, a media representative and a donor family member, symbolically portrayed as equal members on a team dedicated to furthering organ transplant.

The testimonials of morally muscular recipient missionaries amend the official scripts of transplant advocacy without contradicting them. Their entries generally bolster the advocacy project of ‘honouring’ this public good. However, from time to time, recipient testimony becomes a ‘free agent’. Stories are told that show no loyalty to the venerable idioms. New deals are struck with media agents, deals that contravene the polite bounds of the publicity junkets. Some free agent testimony is merely ambiguous; some is rather pointed in its challenge to the promotional public sphere.

An ambiguous entry is the 100 testimonials published in a book called Heroes in 1998 (a re-assignment of the term most often reserved for donors). These testimonials were gathered by dialysis professionals as “narrative therapy” and then published as a “patient manual” for distribution to dialysis and kidney transplant patients. The testimonials were not selective. Narratives of the young and the old, successful transplants, failed transplants and multiple transplants, renal patients awaiting transplant and renal patients declining transplant were all included.

People say, why don’t you put in for a kidney?” No, kidneys are a lot of problems, and I could never take a kidney and it not agree with me, and then be put back on dialysis. No, I’d get a gun and shoot myself. (p70)
Heroes featured tales of depression, tiredness, isolation, medical incompetence, non-compliance, technical nightmares and slow, monotonous days as well as unquenchable spirits, steady progress, supportive circles and blissful transformation. Sometimes the unquenchable spirits belonged to dialysis patients; sometimes the technical nightmares belonged to transplant recipients. Other than a brief foreword, there was no authorial guidance as to how these narratives should be read. The Heroes publication was never intended for a general market. It made the same rounds as the diverse health communiqués, but came calling as a ‘free agent’ rather than a contract player, offering a subtle reminder that ‘feeling rules’ are negotiable.

On occasion, free agent testimony does make its way into mainstream media. The press release and the public sell are left behind in favour of ‘a good story,’ and the story sometimes rushes in where transplant advocates would rather not tread. Public testimony that leads to the disclosing of recipient or donor identity is a case in point. When 11 year old Sandrine Craig died in a school bus accident, her mother Diane not only decided to donate her organs, she also became a very prominent advocate for organ donation, telling her story in various media, lending it to TGLN, and using it to found her own organ donation awareness organization, “Sandrine’s Gift”. One rendition of her story, told by a journalist in a magazine article, convinced recipient Anna Foglia that her new heart and lungs must have been Sandrine’s.

Anna contacted the journalist who for five years acted as an intermediary between donor mom and recipient, relaying messages and gifts, updating health status, vouching for character. All three were now convinced that Sandrine was Anna’s donor, although officials would not confirm it. A policy of strict donor/recipient anonymity guides both
the ethics and the marketing of this public good. The two women, and the intrepid journalist, finally met. Details and photos of their encounter were published in a two-page Toronto Star article with the headline “Joined at the heart” (Carter, 2005). Their “miraculous” story was printed with the appropriate caveats about anonymity and a promotional insert from TGLN regarding shortages, donor cards, religious endorsements and contact information. But despite this addendum, the story reveals the potential of transplant testimony to transgress official strictures.

One type of testimony that is seen as particularly transgressive is the circulation of personal stories of organ failure, on websites and in the press, that seek or generate offers of living donations. Officially, testimony may be used to document the individual quest for health, but not to further it. The ethical crux of the matter, according to TGLN executive director Dr. Frank Markel, is that “people who are well educated would have an advantage because they could write a compelling story about themselves” (Connor, 2006). Clearly, well-educated people regularly write compelling stories about waiting patients, Markel’s organization is a primary producer of such stories. But the promotional mode of governance envisions the public sphere as the marketplace for public goods, not the bazaar of private goods and private stories.

However, the power of the personal transplant story (a genre made familiar and beguiling in large part by the concerted efforts of the transplant lobby) can exceed the bounds that elites would place on it. In the spring of 2003 mainstream press reported on Mac Dickson, a dialysis patient in Orillia, Ontario, who had struck up a cyber friendship with an American couple on a Christian chat line (Avery 2003). Discussions revolved around shared interests in boating and fishing, spiritual matters and the social, physical
and emotional challenges of end-stage renal failure. In the spring of 2003, Ross Caffee, a trucker and an ex-convict converted to Christianity while in prison, told his wife to type a message: “Tell Mac I’ll give him my kidney”. The transplant took place in Toronto. Mac Dickson is not on the roster of TGLN speakers. A subsequent article in an American newspaper with the headline “Organ Donation comes with a price” documented the lingering pain Caffee felt on the job and the $18,000 he had accrued in lost wages since the operation (Alongi 2003). But the story received positive play in Christian media (Listen Up television program, Crossroads Ministries, airdate July 3, 2003) and Caffee himself dismissed the ethical concerns about the solicitation of donors and the costs to donation. “The benefit to organ donation,” he said, “is spiritual” (Alongi 2003).

Transplant Miracles

If there is one constant to recipient testimonials – be they managed, missionary or moderately transgressive – it is the appellation of ‘miracle’ to describe their receipt of an organ, their new found or regained health, their escape from death and their felt affinity for their donor. Anna Foglia and Diane Craig are said to “share a miracle” (Carter 2005). The Canadian Transplant Games titled its relay race the “Miracle of Life Relay”. In 2003, the Kidney Foundation of Canada named their Gala fundraising dinner “Celebrating the Miracles” and produced a glossy program book that featured transplant testimonials as sidebars on every page. The designation of miracle is also a press favourite. “Her ‘Miracle’ Gift,” reads a 2002 Toronto Sun article that details the liver and pancreas transplants of 16-year-old Haley Millman. Says Haley’s father: “A family
turned their tragedy into our miracle, and it is a miracle” (Green 2002). “I was his Christmas miracle,” runs the headline of an article in a weekly suburban Toronto paper. The article documents a women’s decision to donate one of her kidneys to a co-worker (Lavoie 2005). So commonly are transplant and miracle correlated, that the Toronto Star’s daily awarding of “darts” and “laurels” to names in the news saw this 2005 “laurel” to Xander Dolski: “For being a miracle; the Winnipeg infant was sped from womb to operating room for a heart transplant. Eight weeks later, he was well enough to make a public appearance.”

More than a moral tribute, the characterization of transplant as a “miracle” carries a distinctly religious charge. In casual speech the term miracle can emphasize the improbability of an event. But constantly deployed in the context of life and death situations, surrounded by other markers of sacrality, it comes to imply a phenomenon so unlikely, so preternatural, that one can infer (or at least contemplate) the presence of the divine in the machinations of organ exchange.

The miracle designate draws on the resonance, potency and “putative universalism” that religious language affords (Williams 2003, 2000, 1999). All public claims, Williams argues, must be made in language that is ‘public’, unrestricted to the claims-makers, available widely enough to reach across group lines. He finds religious language particularly suited to this task. “‘Religious language, like every other political language, but perhaps more centrally than some, is multi-vocal’ (2003, 188). But multi-vocality and universalism gives religious language a protean quality, a certain slipperiness that sometimes evades the ideological or hegemonic forces it speaks for. Williams cautions, “those symbols that are more widely shared across a society will
concomitantly have more shades of meaning and nuances of interpretation” (1999, 175). “Once religious language crosses social boundaries, its interpretations, meanings, and impact are open to variation and contestation” (2003, 172). The ‘miracles’ of transplant are an excellent example of the multi-vocality of religious language in public claims-making.

In her analysis of media and organ transplant, Johnson states at the outset: “Americans believe in medical miracles – not in miracles of supernatural healing, but in the rational miracle of scientific, capital-intensive, high-tech procedures” (1989, 1). North Americans do not exclusively believe in medical miracles, at least gauging from their wide-ranging discussions of the ‘miracle’ of transplant, but even if they did, the “medical miracle” is an interesting phenomenon in its own right. What makes a medical procedure a “miracle”, even a “rational” one (whatever that is), and not just a procedure? Miracle comes from a Latin word that suggests wonder. It has traditionally referenced acts or phenomenon that contravene the ordinary course of events, acts or phenomenon that overrule, suspend or modify Nature. A “medical miracle” retains this sense of natural biological bounds and chronological flows being reversed or traversed. It is not the cost, sophistication or exclusiveness of transplant medicine that makes it miraculous, but the wonder of beating hearts in foreign chests, urine produced by a man who hasn’t peed in ten years, and livers severed from their natural connections and carted around in plastic coolers.

The age-old ascription for the overturning of the ordinary course and operation of Nature was divine intervention. In the Christian tradition, miracles ascribed to divinity ‘proved’ God’s existence, or in C.S. Lewis’ subtler rendition, miracles are a more
obvious manifestation of the power of God that is constantly at work. ‘Miracles’ suggest that the course of human affairs, or at least key events in that stream, have God-given meaning and purpose. The “medical miracle” relinquishes this attribution (the doctor now gets to ‘play God’), but much of the broader discourse of transplant miracles retains it.

In cinematic portrayals of organ transplant explorations of pre-destination, divinely orchestrated synchronicity between donor and recipient, are so prevalent that they almost rival themes of organ sales and organ snatching. In these sagas of organ transplant the hand of God is perceived in the inspiration of a particular donor and recipient coming together at a particular moment. Disparate, unrelated lives unravel into each other’s narratives of beginnings and endings; corporeal pieces of those lives are wedged together by the vagaries of time and the violence of their collision. Rather than being seen as random, these collisions are frequently portrayed as purposeful and guided. The ‘miracle’ rests in the divine orchestration of fate. The opening scene of the movie John Q (2002) shows the (eventual) organ donor driving down a twisting highway, crucifix swinging on the rear view mirror. The movie follows the mounting crisis of a young boy in heart failure and his distraught parents. The father’s desperate measures prove of no avail, and at the crucial moment when the boy is about to die, the father, a staunch Christian, states he is “waiting on a miracle”. Moments later there is a flashback to the opening scene as the car careens into a transport truck to the strains of Ave Maria. Against all odds, the donor’s heart arrives in time to save the boy.36

With only a few columns or a 30 second ad spot, transplant advocacy invokes the ‘miracle’ of pre-destination with descriptions of donors as guardian angels or spirits that
‘belong’ to their recipient. “They are your miracle team, Toronto,” writes one newspaper columnist in regards to Team Transplant. He explains that recipient paddlers are “not alone in the boat...for there are spiritual passengers who ride like angels on their shoulders – the anonymous donors who contributed their vital organs so others might live” (Gamester 2000). The Manitoba branch of the Kidney Foundation honours organ donors by affixing their name to the wings of a large angel plaque in their offices (“Angels Amongst Us”, 2006). Recipient narratives frequently reference the donor as ‘their’ angel (see Kendra’s story, Chapter 2). The recurrent insertion of guardian angels and protective spirits into public and private narratives of transplant suggests that donors were ‘chosen’ for a particular recipient, brought to them by a guiding hand that directs the twisting courses of individual lives such that they, miraculously, intersect at their appointed time.

Cultural familiarity with the healing miracles of Jesus’ ministry and the miracle of his resurrection is another valence of the transplant ‘miracle’. Healing, particularly when it is rapid and radical and occurs in situations pressed close to death and despair, has an affinity with the kind of healing Jesus performed on others and experienced himself in the resurrection. This affinity is what allows newspaper headlines to tout organ transplant as “triumph over death”, and what prompts many recipients to recount their recovery as “miraculous” (“Organ donations: ‘triumph over death’”, 1999).

But transplant miracles do not just harken to these traditional understanding of miracles (as preternatural events, divinely guided or inspired, or as spontaneous healing or resurrection in contravention of Nature). There is a contemporary religious discourse reshaping traditional understandings of miracles. In this ‘new age’ doctrine, miracles are
described as shifts in perception that allow individuals to extend love to their brethren more fearlessly and utterly in what is ultimately a radically connected, monistic world. “The shift from fear to love is a miracle” (Williamson, 1996, 23). Miracles are not aberrations from nature, but expressions of our truest nature, for humans are, fundamentally, loving, spiritual, child-like creatures. “Miracles occur naturally as expressions of love. The real miracle is the love that inspires them. In this sense everything that comes from love is a miracle” (“A Course in Miracles” quoted in Williamson 1996, 1). God is central to the miracles of this modern ethos, but He endorses rather than directs. It is individuals who are the agents of miracles:

The world needs healing desperately…people know this, and millions have prayed. God heard us. He sent help. He sent you.

To become a miracle worker means to take part in a spiritual underground that’s revitalizing the world” (Williamson, 1996, 68).

This theology of individual miracle workers who conquer their fears (and the correlated false teachings of competition, struggle, sickness, finite resources, limitation, guilt, scarcity and loss) and draw on love as their lens on the world and its peoples has its impetus in A Course in Miracles. Published in 1975 by two professors of medical psychology at Columbia University (one of whom was said to have “scribed” the text dictated to her by a voice she identified as Jesus), the Course consists of an explanatory text, a workbook with daily applications of the text’s insights, and a teacher’s manual for imparting the wisdom to groups of students. The Course circulates worldwide (in excess of 1.5 million copies) and is frequently taught in an ‘instructional’ mode. Some scholars of the New Age consider this text the movement’s most obvious choice for “sacred scripture” (Hanegraaff, 1996, 37).
The Course has been alternately panned and embraced by Christians, but in the early 1990s its influence was extended beyond the purview of both Christians and New Age devotees when Marianne Williamson published a wildly popular, personalized, self-help version of the Course entitled A Return to Love: Reflections on the Course in Miracles. Return to Love spent 39 weeks on the New York Times best sellers list in 1992 and has sold over 3 million copies. The author appeared on a number of American news programs and talk shows, including the Oprah Winfrey show, making Return to Love one of the first books to be endorsed by Oprah. Currently Williamson hosts a talk show on the Oprah & Friends radio station.

The call for spiritualized individuals to generate the miracles of this world by extending love in all circumstances to all people is easily correlated to the donation of organs. Emphasizing the need to identify less with our bodies and more with our spirits, Williamson writes, “to see the body as a means by which the world is transformed, and not an end in itself, is a healthy perception of the body” (226). Organ donation can in fact strengthen and solidify this contemporary religious current. A staunch advocate for transplant, Oprah has often featured the “miracle” of organ donation on her television program, framed by her canonical views of the ways pain and suffering provide the crucible for growth, wisdom and love-filled redemption. In January, 2008, on a segment entitled “Medical Miracles”, Oprah featured Dr. Oz, “America’s Doctor”, discussing 21-year-old organ donor Jason Ray and the ripple effect both his organs and the subsequent donations his media-disseminated story inspired. Oprah’s mantras and Dr. Oz’s enthusiasms marry the “miracle impulse” of love, the medical marvels that overturn Nature, and the act of organ donation.
When George donated his kidney to Candice (see Chapter 4) the imperative of a miracle, as framed in these popular theological discussions, was a primary consideration. George had taken the Course in Miracles, pondered Neale Donald Walsh’s *Conversations with God*, and was particularly captured by the distinctions made between actions inspired by fear, and those dictated by love. At one of the discussion groups he attended a woman pointed out to him that thoughts are sponsored *either* by fear or by love:

‘It’s not a continuum. It’s an absolute. It’s either love or fear.’ And I knew that instant, that very instant, that up until then everything prior to that had been driven by fear. I had no idea what love was. And that was the day that it turned around. That I turned around.

This epiphanic moment remains an important measure of George’s actions and intentions. The desire to proceed from love and not fear factored heavily in his decision to donate – even in the tensile situation of a failing relationship with a woman he had known for a relatively short time.

For liver recipient Tina Tewes, the experience and expression of organ failure and organ transplant has been governed by yet another hue of the miraculous – the marvellously resilient victim.

You know what – my parents would say it, “here’s my daughter, here’s my son, and here’s our miracle.” Or “this is our blessing, this is our miracle child.”

Or at the [Salvation Army] church: “Oh, isn’t it just a miracle!” Well, yes it is, but….

Doctors: “well, can you go and talk to these patients, go and talk to them and encourage them” – and they did that a lot with me…. And I actually had to stop doing that because it reinforced it.

And all around. And that was an image I felt I had to live up to, from a youngster on. “Oh, you survived again! You should be dead. You survived again! You should be dead.”

In an era when most children with liver disease simply died, Tina did not.

Doctors had no treatment for the unnamed disease that caused the degeneration of her
liver, but they tried valiantly to address the fallout from this aberrant condition -- the spontaneous and continuous internal haemorrhaging of blood vessels in her stomach and esophagus. From the age of 11 to 16, Tina was a semi-permanent surgical ward at the Hospital for Sick Children in Toronto.

So they would do a shunt or a bypass, in other words, to reroute the blood vessels. And then in time those ones would be built up and destroyed and haemorrhage. The shunts have a shelf life of maybe two weeks, maybe two months. One time the shunt didn’t hold for twelve hours, and one time the shunt held for almost a year. [The doctor] did some trial drugs, which caused horrendous pain. It was to constrict all the blood vessels. Tremendous pain.

When she was a teenager, a risky, experimental attempt to cauterize the blood vessels was undertaken in a 16-hour surgery. It was a qualified success. Her survival was no longer under the daily threat of a fatal haemorrhage, although the Hepatitis B virus she had acquired from one of many blood transfusions now further threatened her debilitated liver. In addition, the precarious condition of her blood vessels required regular monitoring through a scope procedure that was relatively new and had various iatrogenic consequences. She soldiered on, completing first high school and then nursing college, although the attendant complications extended the time it took to do so. At 30 years of age, now working as a nurse, both her liver failure and the technology of liver transplant progressed to the point where transplant was considered the best option. Her first transplant lasted 4 years. She was very sick, thin and tired by the time of her second transplant. She showed me a picture of her mother at her bedside in the hospital, lifting her arm to help her exercise. Her mother’s thumb and forefinger are touching as they wrap around her upper arm.

With my second one, I was really too sick. Because you stopped for everything. Like you stopped—and I’d been sick for so long that my energy level was just… It was hard. Not only hard, it was extremely difficult to come back from that one. It was hard, hard
work. Physical work, stamina work, mental work. Everything. And after the second one, I hit my first depressive state. In all those years, in all those things, even in the first transplant, I never hit a depression state, and I did with that one.

When I interviewed Tina she was in her early forties, her liver currently in good shape, but both knee joints depleted by immunosuppressent drug regimens. One knee was slated for replacement and the other was slated for correction of a previous replacement surgery that had gone very much awry. Tina felt keenly the current restrictions to her physical, social and professional life. Despite the closeness of our age, I spent the hours in her suburban apartment feeling very much her junior, awed and overwhelmed by the immensity of the health hazards she has navigated. At one point she told me the story of an emergency room attendant who looked at the number of admissions recorded on her medical chart and asked her, “What kind of hypochondriac are you, anyway?” I felt a twinge of guilt, because the sheer volume of procedures, viruses, surgeries, complications and medical errors that she related to me – far more than I could ever record here – made me also want to object: “This cannot be!” even when I knew that not only was it so, there were no doubt many details and many layers left out of her account.

‘Getting it all out there’ is in part a strategy to combat the kinds of silence that Tina feels the ‘miracle’ designation has imposed.

I truly believe that a lot of that stuff was held inside. The part that was sad. The part that wanted to cry. The part that was frustrated. The part that wanted the normal life of the average teenager, the average person.

She no longer nurses. Nursing too meant “holding it all together.” The profession itself put her on a pedestal: “cause you’re the miracle, and the stamina, and then ‘oh, and this is our nurse!” Both her nursing career and her miracle status came under fire when she
finally decided to seek help for a long-standing addiction to narcotics. “I couldn’t talk about it,” Tina related, especially to her family. “You can’t go from the miracle and the hero and the person that keeps fighting -- that doesn’t jive. Because it’s like all these people are expecting, expecting so [much].”

The personal and professional crises that followed the disclosure of her addiction, and the depression that followed her second transplant, eroded the identity that the miracle discourse made coherent. The search for a new identity has necessitated new language.

Sometimes you’d just be so mad. You don’t know where it’s coming from. And I’ll say, “I just feel so angry right now.” And I don’t know if it’s because I wasn’t allowed to (so today look out!) or what.

[My addictionologist] said some of it’s trauma work. Because you were a survivor for so many years. And what happened to you is actually trauma.

And I went, “Trauma? What do you mean?”

I’d never clued to that in my life. It put a whole new word on it. He said, “Yeah, you went through traumatic experiences. Life-threatening trauma. And abandonment.” And all these words that were coming into my vocabulary!

AM: you or the people around you didn’t call it that way?

No. Or if they did, they didn’t talk to me about that. Because they didn’t want to have me hear how bad it really was. Even though I kind of heard it, nobody would talk that bit around me. And everybody else would say how proud they were.

Tina now belongs to an evangelical congregation that provides solid emotional support and a wealth of opportunities for spiritual growth. But, as in the past, church members are vociferous exponents of the miracle idiom: “[The minister], she’d say, ‘I love surrounding myself with miracles, and you’re such a miracle, look at you!!’ And she did it for months.” But with new language, and the new insights it has brought, Tina found the resolve to challenge those who would encase her in the confines of a miracle.
She explained that she was a person, and a friend, first and foremost. “Not ‘this is a miracle, she had a transplant and she’s a nurse!’”

“You really taught me something,” her ministerial friend acknowledged.

“Where did the label come from?” I asked Tina, curious how the designation of miracle becomes both so powerfully validating and so resolutely silencing.

I think initially the medical profession. When my parents then did learn the degree of how ill I was and that I survived, of course then the church and the family and the friends went: “Wow! She shouldn’t be here! Whoa!” And then it kept happening.

And then when I went to nursing school and I learn that 90% of people that have one major haemorrhage die, and I went: “Hold on! 90% of people die from one major haemorrhage and I’ve had—I can’t even count how many, never mind small ones. I’m not supposed to be here!”

So part of my brain would think, ‘yeah, I am a miracle.’ But if I believe that then I can’t look at all the other. And I just had this: do the best I can to give back. Then it became that part of me: I had to do the best I can…. Because I had to do everything right to give back to all these people who gave to me.

Rutherford (2000) suggests that the label also comes from a particular propensity in Canada to advocate for the ill with images and narratives of buoyant resiliency. Charitable advertising in the United States, he points out, tended to employ a very “dark aesthetic”, highlighting various “versions of hell” in their calls for aid. However, in Canada “a different tradition of disability advertising has positioned people with handicaps as survivors… Canadian ads were sometimes marred by highly sentimental portrayals of marvellously resilient victims” (126).

Tina’s lifelong passion for the Christian faith, and her active involvement with the Salvation Army and other evangelical denominations, has been a both of source of grief and solace in her struggle to live with organ failure. “I lived this life that if I didn’t smile, you’re in trouble. Because I should be thankful. So if you’re sad or anything, put a smile
or a mask on it. Put bandages on it.” The church was often a powerful force in securing this mask. But ultimately her faith is part of what has allowed her to remove it: “That’s not what God wanted. I’m allowed to have, there’s permission -- you know, God gave you all these emotions.”

The potency of religious language is such that Tina does not have to discard the notion of miracles; she need merely bend it to yet another, less exclusive, task. You may love being around miracles, but my perspective is everyone is a miracle. You just don’t see some of them…. Maybe someone went through something emotionally. And maybe somebody did something else, but you don’t see all the physical effects and it’s not called transplant and it’s not called this. Maybe somebody else came through the slums and managed to get through school and ended up being a teacher and went back there. But we don’t say, “Wow, what a miracle to live where they lived and then to have the courage to come back.” But I say, everybody is a miracle.

The rhetorical language that Tina now questions had, in the past, supported deeply felt dimensions of her subjective self. It also had the endorsement of a vast array of social elites and was constantly promulgated in the promotional public sphere. To bend this language is a Herculean and painful task. It is not done without cost, including the cost of strained relationships with family and friends who do not understand the need to revise long-standing and laudatory narratives. In this sense, Tina’s story reinforces the caution that there are compromises involved in objectifying one’s identity or experience as a strategy for gaining media visibility (see Ginzburg et al, 2002, 9). Miraculous recipient testimonies that sing for the media are, in some ways, a gilded cage.

Against the creative shape-shifting of the religious language of miracle (medical miracles, miracles of synchronicity, healing miracles, loving miracle impulses and miraculously resilient victims) that advocacy consistently applies to the donating, receiving and procuring of organs, there is the occasional nay-sayer. “It shouldn’t take a
miracle,” reads the headline of a newspaper article detailing the campaign to increase donor rates in Ontario by instituting presumed consent legislation (Hauch 2004). This lobby (of which TGLN is notably not a part) serves as a reminder “that advocacy advertising is normally an instrument of domination in a much wider apparatus of disciplinary power” (Rutherford 2000, 10). Advocacy claims and promotional discourse have recourse to legislative clout.

The lobby for presumed consent also intimates a subtle frustration with the religious language used to make transplant’s public claims – the reverent witnesses and communal heroes, the miraculous gifts and noble Samaritans. Not yet formalized or spoken in the media, the phrase “rights and responsibilities” is nevertheless gaining voice in the conversations of transplant advocates. “Rights language,” the alternate vehicle of potent public claims-making (Williams 2003), is poised to make inroads in transplant advocacy. Both religious and rights languages have limitations. Williams (2003) notes the propensity of religious language to silence opposition and divide populations into the elect and unregenerate, saved and damned (172). Rights language, however, “is not a rich language for expressing social relationships which it reduces to the logic of the economic contract” (2003, 185).

Neither language, Rutherford would counter, can efface the “endlessness” of the propaganda colonizing the political, social and moral realms of the public sphere. But Rutherford (2000, 2007) is always cautious about authority’s ability to realize its ambitions. While there can be little doubt that transplant advocacy has “conditioned the behaviours of actors in the public sphere” (Rutherford 2000, xvi), such conditioning is not total, even if it is endless. Transplant advocacy is not univocal. It relies on recipient
testimonials that don’t always speak properly. It preaches alongside other promotional discourses that cast aspersions on transplant even as, collectively, they further a particular mode of governance. It vies with – and indeed fuels – popular renditions of organ transplant that generate fear and dissuasion. It deploys a religious language that in its very reach and resonance leads to variation, contestation and innovation.

1 Speaking engagements and press coverage regularly referred to his ‘walk’ across Canada; official statements described his ‘trek’.
2 I conducted interviews with Duncan (and his son Graham) and learned about the Kris’ Wish campaign through him. Their names are pseudonyms. I have not concealed the identities of other event participants, as I know no more about them than they chose to publicly reveal. I have recreated the speeches from my field notes.
3 Transplant professionals refers here not only to medical professionals, but to all those who participate in transplant’s infrastructure in a professional capacity, i.e. organ procurement staff, health promotion agents, drug company representatives.
4 In some senses, Kris’ Wish is also an instructive example of transplant ‘ritual,’ the subject of the last chapter. There is a lively scholarly debate about the relationship between media and ritual, to which Grimes (2002) provides a careful and considered map. Curiously, whether media are said to validate, amplify, extend, play with or co-opt ritual objects or ritual traditions there is generally a sense that rites are ‘sui generis’. They exist prior to the media interventions laid upon them. (The exception would be equations of media and ritual -- TV viewing is ritual -- which Grimes dismisses as unfruitful.) What separates the Kris’ Wish campaign from the rites and ritualizing described in the last chapter, and from much of the scholarly literature on this subject, is that the media anticipate the rite. They are its raison d’être. In other words, these ceremonies simply would not happen without media coverage, whereas Lady Diana’s funeral, evangelical services on television, cyberspace weddings, commemorations of war dead – even organ donor memorials – would presumably proceed (radically altered no doubt) without media attendance or in non-mediated modes. The tally of 2000 media entries generated by the Kris’ Wish campaign is provided by the Step-by-Step website. Even if exaggerated, my informal sampling of the media coverage afforded the Toronto high school ceremonies suggests that the campaign received widespread media attention.
5 While most pop culture examples discussed in this chapter were ad hoc discoveries or participant recommendations, I am indebted to Anthony Cristiano, Dalhousie University who provided me with an inclusive list of transplant movies, allowing me to discuss this aspect of transplant discourse more definitively. Documentaries about transplant are a particularly hybrid form of entertainment, advocacy and scholarship; they are regretfully absent from this discussion.
6 Coman and Rothenbulher record their “disdain” for such “territorial debates between disciplines.”
mode of governance through the proliferation of civic advocacy in the television era, see Rutherford
(2000).
8 This chronology is drawn from Johnson’s (1989) close review of the popular press coverage of organ
transplant in *The New York Times, Newsweek* and an Austin, Texas daily (*The Austin-American Statesman*).
9 Johnson (1989) provides a detailed review of the press coverage of Barnard’s heart transplants. See also
the extensive discussion of the media coverage of Christian Barnard in Fox & Swazey (1979).
10 Johnson’s (1989) compares four variables in her analysis of press coverage of the Barnard heart
transplants: financial and organizational issues, social issues, alternatives to transplant, procedures and
outcomes (see 96). The last category was by far the most prevalent.
11 Even the national press served up recipient success stories via the Transplant Games. See Maxwell 2005.
12 The lack of a national perspective has been criticized for some time. In 2001, the Canadian Council for
Donation and Transplantation (CCDT) was created as an advisory body to the collective Ministers of
Health in Canada. It initially operated within the framework of the federal government, becoming a
national arm’s length organisation in 2005. As of fall 2007, various levels of government were proposing
the dissolution of the CCDT and the transfer of its responsibilities to Canadian Blood Services (the national
agency that oversees blood supplies in Canada). Presumably, opportunities for a national organ registry,
nation-wide coordination of organ exchange and more uniform and widespread promotion of organ
donation would evolve from this move.
13 Organ Donation Ontario spokesperson Gary Cooper is quoted as saying that the annual budget of 1.4
million covered operation of the electronic allocation system and didn’t leave anything for advertising
(Sivel 2002). The 2005/6 TGLN budget, just shy of $11 million with 1.3 million for communications,
gives some sense of the expansion of ODO’s limited promotional and educational objectives.
14 This is Johnson’s (1989) larger argument and similar arguments can be found in Sharp (2006) who
writes, “an assumption that underlies this book is that organ transplantation defines an intriguing and exotic
milieu in which to explore a highly specialized array of medicalized behaviors and associated ideological
premises” (2). See also Sharp’s (2006) discussion of the growth of the transplant industry (25).
15 Nancy Scheper-Hughes (2000) argues organ transplant reconfigures the existential lived body-self, the
social, representational body, and the body politic. But her assessment of these changes relies on an older
model of power; she is not inclined to consider issues of hegemony (i.e. our compliance in our own
subjugation) or Foucault’s emphasis on the generative nature of power’s strategies. However, her
assessment of the repressive power of transplant markets and circuits may be the most suitable for
considering the global impact of this North American ‘public good’.
16 Illustrative here was the outrage that greeted a federal decision to exclude homosexuals from the act of
organ donation due to the perceived risk of organs being HIV positive. Various press reports insinuated
the exclusion was an attack on the right of homosexuals to be active “citizens”. (“Heath Canada Organ Donor
17 For a fuller description of “faith outreach” by transplant advocates see Chapter 1.
18 See extended discussion in Chapter 1
19 Consider the scene in the video described above, the “Donor Sabbath” booklet described in Chapter 1,
and the use of candle lighting rituals in donor memorial services usually held in Christian churches
20 In Canada there has been one published survey of advertising recall and retention (Environics Research,
2002), but this quantitative study was not designed to measure affective response.
21 Living anonymous donation in Canada is very much in its infancy. Nevertheless a pilot study conducted
in British Columbia found that “an integrated spiritual belief system” were statistically significant in the
decision to offer one of their kidneys to a total stranger (Henderson et al, 2003). More certain are the
Christian affinities of transplant recipients that participate in transplant advocacy. All of the participants in
this study were of Christian heritage. Field observation and casual conversations suggest that the vast
majority of recipient activists are of Christian heritage or affiliation.
22 See Williams (2003) for a discussion of the bridging potentialities of religious language, and the limits to
political claims spoken in languages of identity politics, scientific expertise and specific interests. See
Zwissler (2007) for a discussion of the ways the language of ‘spirituality’ bridges religiously and politically
diverse activists.
23 For instance, “rewarded gifting”, a euphemism commonly used to describe various payments made to
donors (funeral expenses in some American states, donation related expenses for living donors in Ontario),
demonstrates the way sacralized language continues to describe the transaction even when it begins to
transgress the limits many Christians would place on this practice. Sharp (2006) notes that in the last five years financial incentives have surfaced as the most popularly proposed solutions to close the scarcity ‘gap’ (18).

24 See for example the television B-roll produced by communications firm O’Doherty & Associates for TGLN’s April 2003 NOTDAW campaign (O’Doherty & Associates, n.d.)

25 The quote is from a news article discussing Don Cherry’s controversial remarks about hockey players from Quebec (“CBC to use seven-second delay for Don Cherry”). For a more extended discussion of Don Cherry’s position in Canada’s cultural politics see Gillet et al, 1996.

26 Safe sex, vaccinations (including the new HPV vaccine), anti-smoking, designated driver and physical exercise campaigns are some examples. Sharp (2006) (accurately) notes that this segment of the population “defines the ideal donor category” (19). However, the average age of cadaveric organ donors is steadily on the rise due to medical willingness to procure and use older donors. The youth market, it would appear, is important symbolically, culturally, and governmentally, as well as practically.

27 Against the proscribed feeling rules that contend organ donation eases grief, Sharp’s (2006) ethnographic research with donor kin suggests “the construction of the transmigrated donor soul can initiate a period of ceaseless mourning” (31).

28 The criminal status of the man who received the first hand transplant was frequently mentioned in press coverage (see Campbell 2004). See also the coverage of a Toronto murderer who was also a heart recipient (Bradley, 2001).


30 Nancy Scheper-Hughes (1996) documents the proliferation of organ stealing rumours across the poor communities of the globe. She argues that the rumours, if not literally true, accurately reflect social and biological realities in those communities – the medical maltreatment of the poor, the international adoption of destitute children, political disappearances and the general violence that poor bodies are subjected to. Thus the sense of alarm about body parts is justifiable. Her argument is persuasive but doesn’t help explain the circulation of similar rumours (and their elaboration in film and television dramas) amongst the affluent and educated of peaceful North American democracies.

31 Ironically, if health promotion advocates could eliminate ‘risky’ behaviours from the populace at large, they would not only shrink the number of transplant candidates they would vastly reduce the pool of available donors. Bill Barrable, executive director of BC Transplant Society noted in 2007 that only 15% of organs recovered and transplanted are from motor vehicle accidents, down from 45% about 15 years ago. In BC the potential pool of deceased donors has dropped about 60% since 1990. “This is great for public health,” he states, “but not encouraging if you are waiting for an organ for transplant” (“Gift of Life”, 2007).

32 For instance, the CNN medical program “House Call” (air date July 10, 2004) saw this exact question put to transplant surgeon, Dr. Kenneth Newell, director of the Living Donor Kidney Transplant Program at Emory University. Yahoo Answers, a popular internet site billed as the place people “get real answers from real people”, also features a query about the awarding of organs to smokers and drinkers (“Organ Transplant Question”).

33 My review of patient communiqués focused on the national Kidney Foundation publication (“Kidney News”) and that of the Central Ontario Branch (“The Kidney Kommunicator) as well as the St. Michael’s Hospital Transplant Centre publication, “Transplant Talk”.


36 See also Jesus of Montreal (1989) and 21 Grams (2003) for explorations of similar themes, albeit less heavy handed. Television has its own versions of transplant events best explained by recourse to
providence; several episodes of “family-friendly” PAX television show “It’s a Miracle” featured stories of the startling convergences of organ donors and recipients.

37 For an excellent discussion of the ways Oprah’s book club has functioned as a “canon for contemporary living” that celebrates resiliency, diversity and a redemptive worldview, see McClymond (2002).

38 A topic of intense discussion at the interdisciplinary conference “Intersections of Life and Death” held at the University of Toronto, 2007. Also a proposed research stream of the Loeb Research Consortium in Organ Transplant and Donation, situated at the University of Ottawa.
I began this study with the hope of shedding light on two things: the construction, experience and interpretation of religion in the lives of a limited number of organ transplant recipients and the broader cultural production and elucidation of religious significance in the transplantation of organs. Other than in the initial conceptualization, I have not been able to hold these two sorts of religious narratives and performances apart; my study participants were simultaneously producers, consumers, subjects and targets of transplant’s public rituals and sacralized presentations in the media. One of the key goals of the study was to expand the scope and compass of religion in the province of organ transplant beyond the typically narrow focus on religious authorities, religious organizations and religious injunctions found in bioethics literature and procurement publications. I also wanted to make religion “present” in ways that the typical concern of transplant scholars for religious inheritances and hangovers did not.

This expansion of the purview of religion in organ transplant has at times become unwieldy and would benefit from summary. The theological meanings of organ transplant (in the Christian tradition) were most thoroughly explored in chapter one, through a review of the doctrinal debates and transplant-related exegesis that appeared in Christian journals and ethics publications in the years 1980-2000. Theology has been described as “faith understanding itself” and in this chapter I try to elaborate how the Christian faith refracts its understandings of itself through the technology of organ transplant.

Chapter two introduces the more amorphous and unbounded concept of “spirituality” into conversations about religion and organ transplant. I describe the participants in my study as “spiritual seekers” trying to find out why they were still here
when they should have been dead. “Spirituality” takes religion past institutional loyalties, inward to the individual and subjective experience of sacrality and outward to a diverse marketplace of cultural resources that both nourish and are nourished by the spiritual life. This chapter explores recipients’ spiritual life as it emerged in the crucible of death anticipated and averted. I pay particular attention to recipients’ engagement with the spirits of their deceased donors and their intimation of spiritual bonds in the transplant community, bonds built on shared experiences of loss and renewal. I also engage eschatological hopes and understandings, both those of recipients and those inferred in the cultural discourses about organ transplant. I argue that the bodily resurrection as an organizing construct of theology, eschatology, ritual practice and proper conduct is being countered by the rhetoric of the Gift of Organs with its alternate constructions of an immortal soul, its alternate ritual practices, and its alternate visions of good conduct.

The emphasis on spirituality continues in chapter three where I explore the ‘wondrous’ -- visions, presences, unusual emotional states, dramatic conversions, prayers answered with prescient timing or astonishing results – in the narratives of transplant recipients. Such episodes were intimately tied to their illness, their transplant or its aftermath and invariably recounted as wondrous, in some sense of the word. The wondrous encounter afforded insight into the construction of character and virtue in recipients’ lives, opening the discussion of ‘religion and transplant’ to questions of morality and agency.

In chapter four I examined the ritual performances of organ transplant, some explicitly liturgical, some borrowing traditional religious forms for other purposes, and some designed to consecrate a “sensuous civil religion.” Exploring the rites of organ
transplant uncovered still more aspects of the play of religion in the exchange of organs: the performance of mourning and commemoration, the sacrament of healing enacted on individual, communal and ancestral bodies, the ritually sanctioned interaction of strangers and the ceremonial making of bio-citizens.

Finally, I expand the scope and compass of religion by considering the construction of religious culture via contemporary presentations of organ transplant in various media. This is the terrain of chapter five where I track the religiously inflected images, motifs, testimonials and moral logics that shape the public displays of and social conversations about organ transplant. The multiple resonances of the “transplant miracle” are unpacked to show the ways organ transplant is religiously encoded – and the ways ‘folk ontologies’ are enlivened and expanded by the technology of transplant.

The foregoing encapsulates what the study has uncovered: an expansive and lively field of religious meaning and activity engendered by organ transplant in the lives of these recipients and in North American cultural life. In what follows, I would like to revisit the larger questions and dynamics illuminated by this phenomenon. The ‘religion of organs’ speaks to issues of agency and power, hegemony and resistance, and the place, form and function of religion in contemporary North American society.

Most emphatically, the rich religious narratives and copious religious ‘noise’ insist that ours is not a secular society, that religious language still has societal reach and resonance and that individuals still find religion an evocative register for the existential tangles of body and person, self and other, illness and health, death and survival. That the body, especially in times of transition, disruption, or dissolution, continues to be
central to the construction of religious meaning and ritual enactments is not particularly surprising. Biomedicine and biotechnologies are complicit in this meaning making and ritual play – be it donated kidneys named Rainbow, donor/recipient pins traded at a Mennonite church, donor spirits that kick recipients out of bed, hospital orderlies praying righteousness over recipients or passion plays of organs unfolding in movies and advocacy scripts. On the one hand, this makes sense: contemporary bodies are inextricably entwined with biomedical domains. On the other hand, biomedicine has often been figured as one of the solvents of religious belief, practice and influence. Scholars have more often sought religious bodies in fields or practices thought to contest biomedicine -- faith healing, alternative medicine, home birth – than in those that celebrate it. The contemporary religious body that emerges from transplant medicine problematizes a narrative of modernity that casts secularization as the plot line and biomedicine as one of the main characters in that drama.

Transplant’s religious body is practiced and produced by deceased donor families, living donors, recipients, transplant clinicians, procurement professionals, government officials and non-profit health organizations. It is engaged, enlarged and embellished by an assortment of ecclesiastical figures, cultural commentators and entertainment industries. Acknowledging the diversity of influences that generate this religious body is important because anthropologists and sociologists of transplant often attribute the sacralized discourse to procurement agencies and describe it as a fetishism of organs that masks the commodification of the body, the individuated donor, and the constructed nature of organ ‘shortages’. This is not, per se, untrue – but an appreciation for the
breadth of this sacralized discourse, its many sources and varied voices, develops a more nuanced understanding of authority, agency and power.

To be sure, procurement agencies and related government ministries are prolific producers of transplant’s sacralized discourse. Their intention is to ‘sell’ this ‘public good’ through the discipline of marketing. Public goods are “products” born of “surveillance” (task forces, commission reports, statistical surveys, questionnaires, polling), “spectacle” (advertising, ritual, publicity, celebrity) and the ‘science’ of consumer marketing (“product, pricing, promotion, and placement”) (Rutherford, 2002, 6). The sale of public goods trades in a moral logic of sin and salvation, and transplant advocacy that circulates angels, Good Samaritans, candles and gifts of life alongside the sin of needless death partakes of this moral logic. Procurement agencies, and the transplant professionals and government officials that support them, are authorities with power -- both resources and reach.

But power also works through them. It is important to place the sale of organ donation as a public good in a broader marketplace of public goods – clear air, drug free bodies, harmonious nations – all similarly marketed. Civic advocacy of this nature proliferates and penetrates with the rise of the television commercial (Rutherford, 2002). While it may (or may not) succeed in selling its products (people may quit drinking and driving, recycle their newspapers and donate their organs), what it simultaneously produces is citizens and citizen collectives defined by the ‘purchase’ of public goods rather than by rational, critical debate about the interests they hold in common. The atomized or cyborg body, the view of humans as collections of spare parts, is not effectively advanced through the sacralized discourses of transplant advocacy: the
transaction is too reified, the donor too sanctified, the rejuvenated recipient too miraculous. However, the sacralized discourses of transplant advocacy do effectively advance a particular kind of civic body – one tantalized by the “reek of virtue” (Rutherford, 2002) emanating from public goods and nourished by their consumption. Either construction of transplant (spare parts or public goods) might convince us to divest ourselves of our organs, but it is important to be clear about which is being activated if we wish to also understand the generative extensions of our divestment.

Anthropologists and sociologists of transplant have also charged this biotechnology with instigating a stubborn refusal of death and inculcating a collective quest for immortality. Again, it is helpful to place transplant technologies in a broader context and scrutinize more closely the religious nuances of its discourses. Foucault (1976, 2003, 2007) has made a persuasive argument about a novel force of propulsion (which he termed “biopower”), an “administration of life” that proceeds through both the disciplines of the body and the regulation of populations. Biomedicine and biotechnologies can be central extensions of this power. I would argue that the transplant endeavour has been driven forward by the ascendancy of biopower in certain late 20th century collectives, not by a sudden surge in individuals hoping to evade death. It has involved new truth discourses about the vitality of organs, new strategies for intervening on collectives in the name of life (organ procurement agencies, organ donor cards, transplant teams, brain death legislation), and new ways of individuals working on themselves, to accept organs, but also to proffer them. Live donors, donor kin and organ recipients can all be viewed as biopower’s subjects; the desire to “ensure, sustain, and multiply life” (1976, 138) is enacted and extended through each population.
The relentless strategies, techniques, truths and practices (organ donation and transplant among them) dedicated to making individuals and populations live is not totally removed from quests for immortality. However, seeking immortality (or ‘more life’) through transplanted organs involves a nexus of moral ascriptions and cosmological understandings, as would the search for immortality in a religious tradition. Organ recipients articulated a complex set of ethical prescripts. Their transplanted organ obliged them to “live as fully as possible”, attending to the present moment with vigour and verve. It necessitated the cultivation of virtues born of the long-haul: perseverance, discipline and courage. They were to recognize and nurture the “spirit” of transplant collectives. They were to cement the social place of organ donors through public commemorative rites, and engage the spirit of their donor in their personal life through more private rituals of remembrance. They were to ‘give back’ – or pay forward, as it were – their gift of life by administering more life through patient mentoring, health promotion and organ donation awareness. Theirs was a version of what Rose (2007) terms a “novel somatic ethics with obligations as well as hope” (8) that has accompanied the extensions of biopower. The hope for a transplanted organ is accompanied by a litany of moral, ritual and spiritual obligations. Conversely, the obligation to donate one’s organs at death is accompanied by an array of hopes about the extended life of the donor in the spiritual life and social circles of the recipient, and in the civic life of the nation.

How much agency is granted religious subjects when their vocabularies and cosmologies are so intimately shaped by the sorts of powers described: the selling of public goods, the persuasions of biopower? Although I have not framed it this way, some might ask how authentic can their religion possibly be? This tension between active
agent and scripted subject is inherent in my study. Despite the intricate integration of the private and public renditions of the religious narratives of transplant, two very distinct methodologies are employed to collect them. The process of interviewing accords a distinct agency to the narrator and consciously works to avoid the domination of either the interlocutor or some critical, theoretical frame. Some ethnographers have referred to the product of this intense interaction as a “third subject” (Myerhoff, 1987) – neither the unadulterated person of the interviewee nor the pure product of the interviewer’s acumen or interpretation. Cultural studies generally does not worry about the subjectivity of its media texts. Scrutiny and dissection are the order of the day.

The two methodologies I have employed in this study have sometimes produced distinct, if not conflicting, portraits of organ transplant recipients and their religious lives. In chapter three, the ethnographic accounts come to the fore, and recipients emerge as active moral agents responding to emotive religious encounters, engaging dominant discourses about ‘health as morality’, practicing virtues that emerge from their particular lived experience, and constructing new moral communities that protect, articulate and disseminate the ‘goods’ they have found in the “chronic-ness” of organ failure and the counterweight of organ transplant. In the study of transplant advocacy presented in chapter five, recipients are read as contract players (and occasionally other characters) scripted into passion plays of organs and interpellated by media identities that are ‘ready-made’, sponsored by social elites, and given moral authority by the religious vestments they sport. Although recipients are exceedingly active in this cultural and religious work, the work itself is said to produce ‘feeling rules’ that make the notion of individual, subjective religious emotion or experience problematic.
Rather than aim for a definitive resolution, I have let this tension stand. I have tried to point to some of the gaps power inadvertently generates and the resistances agents mount. There are intimations that religious language might contest, or at least complicate, the sale of public goods. I try to explicate the elisions—the plethora of transplant ‘sins’, the multiple inflections of miracle, the unruliness of testimonials. Religion, most often Christianity in my examples, is a ‘swing voter’ in “the politics of life itself”.

Christianity can be ambivalent about the project of “making live” – particularly as it deployed and developed in organ transplant. Christian understandings of death are a case in point. Death has a double meaning in Christian scripture and doctrine: it is both enemy and sacrament. The view of death as the enemy can be a staunch defender of the power to administer life. But death in the Christian tradition also represents finitude and mystery; death calls one to God. Some commentators insist that it is Christian to consider the meaning of mortality, to want to reflect on something beyond the continuation of physical life and to hope beyond earthly existence. Such a stance is inherently antithetical to the administration of life. Perhaps it is precisely because Christianity is a swing voter in these politics that the experts and administrators of transplant work so diligently to win Christian hearts and minds.

Nevertheless, gaps and elisions can be illusory. Nowhere was I more struck by the impossibility of escaping biopower’s pastoral reach than with Tina’s determination to challenge the transplant “miracle”, the posture and persona of the miraculously resilient victim constructed and authorized largely by somatic experts and disseminated through the disciplines of marketing. “What happened to you is actually trauma,” Tina’s
counsellor tells her. “I’d never clued to that in my life!” she explains. “It put a whole new word on it…life-threatening trauma…abandonment…all these words that were coming into my vocabulary!” With this new language she speaks back to the conducts called forth by the miraculously resilient victim. I had originally read this as a small victory, an escape of sorts from the desire to administer life inherent in the circulation of the transplant miracle. But the language of trauma and abandonment is equally a purveyor of biopower. It is issued by different authorities than those that circulate the transplant miracle. It works on subjects differently (and calls them to work differently on themselves). But the language of trauma, the construct of addiction, the expertise of the counsellor is similarly bent on the administration of life, on “the conscious and calculated management, maintenance, modification and manipulation of our somatic existence” (Rose, 2007, 105).

Tina was explicit that she was speaking back to the transplant miracle, and I too would like to make explicit the conversation partners that this study has been speaking with. The ethnography of organ transplant, much of it conducted by medical anthropologists, has largely shaped my understanding of the transplant endeavour and transplant populations. Their arguments about this technology are, centrally, what this study speaks back to. I read their insights through the lens of religion. I also believe this study of religion and transplant can speak to transplant’s somatic experts, cultivating a more nuanced and sensitive portrait of the religious bodies they administer to. I have tried to bring the fields of religious studies and cultural studies into conversation with each other: asking about the place of cosmology, eschatology and ritual in emergent biosocieties and in projects of biological citizenship, asking about the place of biopower,
pastoral power, and civic advocacy in the collective religious expressions and individual religious narratives about organ transplant. Finally, I have tried to listen to, and make heard, the religious lives of these particular transplant recipients.
Appendix 1

The journals *Christianity Today* and *Christian Century* provided the bulk of articles considered in this review. Both are popular weekly journals, *Christianity Today* having circulation of some 170,000, *Christian Century* considerably less but still widely read and influential. However, their readership, their denominational affiliations and the issues they accent sharply distinguish them. *The Christian Century* is the older of the two. Originating in 1884 as a Disciples of Christ denominational magazine, it changed its name to *Christian Century* in 1900 in response to the great optimism of many Christians at the turn of the 20th century that Christian faith and modern progress could be both harmonious and mutually beneficial. In 1916 Charles Clayton Morrison purchased the magazine. He labelled it ‘undenominational’ and championed “a progressive” and “constructive” vision, an “optimistic and hopeful, tolerant and liberal” Christianity (Meador 2003, 275).

Under Morrison’s fifty year tenure the journal advocated higher criticism of the Bible, extolled the acuity of Darwinism as both historical explanation and a rule of contemporary life, employed the growing science of psychology to understand the ‘inner life’ and further projects of the ‘self’, and campaigned for social and political causes sympathetic with the Social Gospel movement. A common target for criticism by fundamentalists in the early 20th century, the magazine has nevertheless continued to flourish, remaining the major independent publication within ecumenical, mainline Protestantism in the United States. (See Meador 2003.)
Christianity Today was founded in 1956 by the evangelist Billy Graham to provide a voice for the evangelical Christian community and, indeed, to provide a counter-point to the dominant Christian Century. In its early years circulation was heavily subsidized, however, in the early sixties it successfully made the shift to a voluntary subscription. Its founding editor, Fuller theologian Carl F. H. Henry, valued “journalistic reporting, scholarly credentials, and, most of all, serious debate” (Board 1990, 130). Henry’s successor, Harold Lindsell, was “more explicit and aggressive both in ecclesiastical and political conservatism” (Marsden 1987, 260) but the magazine has not been univocal, for instance both promoting and criticizing the Intelligent Design movement. The magazine consciously highlights issues of importance to evangelicals, launching readership surveys in the 1980s to determine reader interest for specific articles and features (Board 1990, 131). The magazine has several sister publications and a very active website. (See Board 1990, Marsden 1987.)

In Canada there are three main Christian journals – The United Church Observer, The Anglican Journal and the Catholic Register. None of these have anywhere near the reach and presence of the two American journals reviewed and only one, The Anglican Journal, is archived in a searchable electronic database. For this reason, it is the sole Canadian journal included in the literature review.

Organ transplant did surface in other Christian journals and I include articles from the Journal of Pastoral Care, U.S. Catholic, Greek Orthodox Theological Review and Anglican Theological Review. The journal First Things is somewhat of a cross between an academic journal and a theological journal, contributors working in a
tradition of intellectuals presenting a Christian critique of contemporary society. I have quoted quite extensively from Gilbert Meilaendar’s article in this journal.

The blend of theological conviction and academic rigour is also apparent in ethics publications written by Christians. I review the work of several Christian ethicists on organ transplant (see Childress 1991, 2001; Ebersole 1988; Jung 2001; Mongoven 2000, 2003; Ramsey 1970; Sanders 1995; Verhey 2000) and also include the work of a non-Christian, well-known philosopher and ethicist Hans Jonas (1974).

In addition, Christian voices are heard at gatherings dedicated to exploring the relationship between faith and organ transplant. These are a relatively new phenomenon and I include two published accounts of such ‘multi-faith conferences’ (see Bradford Hospitals NHS Trust, 2000 and Canadian Council for Donation and Transplantation, 2006). Christian views on organ transplant are also regularly sought by transplant professionals and published in clinical publications (see Canadian Council for Donation and Transplantation 2006 for a helpful review of this literature). My emphasis has been on what Christians are saying to Christians, and I have generally not included this literature (the exceptions being Teo 1992, and Pope John Paul II 2000).


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