10. Part of the Plan?

Faith In and Through Solid Organ and Blood-Forming Stem Cell Transplantation

Laura L. Heinemann, Creighton University

Introduction

[1] Those who participate in solid organ and blood-forming stem cell donation and transplantation, whether as patients, caregivers, or clinicians, necessarily encounter complicated questions to which there are few clear, easy, or uncontroversial responses. These conundrums often stem not only from the clinical and prognostic uncertainties that still permeate this relatively new and ever-evolving collection of medical technologies (Maynard), but also from dilemmas concerning socio-cultural meanings and understandings of death (Lock 1996, 1997, 2000, 2002), the role and status of organ and tissue donors and donor families (Sharp 2001, 2006), and how best to manage shortages in available resources
when compared to the demand for transplantation. For example, patients and loved ones seeking transplantation, and the clinical professionals who carry out the procedures, all deal on a daily basis with large social problems involving shortages in transplantable organs (Browning and Thomas; Marshall; Ubel and Loewenstein), as well as difficulties securing financial coverage of the accompanying health care costs (Jones and Egan; Kasiske et al.). Such problems are enmeshed with the very poignant matters of life and death, and raise important questions about how members of this population actually do approach the unknowns and quandaries surrounding their experiences, even as they aim to move forward through the transplant process: What carries persons through the uncertainties of transplantation? What matters most to those facing the highest stakes? How do persons understand the meaning and role of relationships over the course of their illness and transplant? What motivates participation and endurance through difficult times?

[2] This article will mark a small step toward better understanding the lived experiences – what medical anthropologist Arthur Kleinman calls “the multiple cultural realities of everyday life” (42) – among transplant patients and caregivers facing illness, risky and painful procedures and treatment protocols, even possible death either for themselves or for their loved ones. Throughout, this article will do so by drawing upon qualitative data, gathered through ethnographic fieldwork among patients, caregivers (which in a few cases also were living organ donors), and clinicians, to describe some of the day-to-day experiences of those who are closest to and most personally vested in transplantation. It will highlight evidence that persons making the precarious journey through the transplant process often do so in and through a sense of faith. Here, I use the term “faith” in a double sense, drawing primarily upon its reference to religious beliefs, but also employing its reference to trust in transplantation as a powerful and life-saving endeavor. There, of course, is great diversity within the transplant community, and personal vantage points are shaped not only by religion and interpretations of divine will, but also by socio-cultural contexts, historical moments, political economic factors, and kinship and social networks. While a full account of these factors is beyond the purview of this article, I hope to emplace sufficiently the lives of the persons described below so as to make clear the significance of interpersonal social relationships (on a smaller scale) and sociality (on a grander, macro-social scale) in faith. I will suggest that, rather than being founded in a purely personal, individualistic relationship with the divine, a faith-filled perspective on transplantation also corresponds with a deep engagement in the overarching social moral obligations that pervade and help to sustain this high-tech medical practice.

Faith Imagery and Public Morality in Transplant

[3] In the contexts within which I conducted my research, as in many other socio-cultural contexts, it is not at all uncommon for persons to draw connections between religious faith and morality. Religious beliefs about the will of a higher power can powerfully shape ideas about what is good and right, and what persons ought to be or do in relation to one another. As I will point out below, I found evidence that transplantation engages with this [religious] faith-morality connection. In the cases I will highlight, persons might be said to practice their faith through participating in transplantation. On the other hand, I also found evidence that transplantation resonates with broader social ideals and public moralities (again, concerning
what is good and right, and what persons ought to be or do in relation to one another),
which can remain consistent across differences in particular religious beliefs. This is
especially relevant, given the fact that so many continue to put their faith (i.e., trust) in
transplantation in spite of the conundrums associated with it, which I highlighted at the
outset of this article.

[4] In order to more fully analyze the interconnections between transplantation and faith (in
both senses of the term I highlight in this paper), I will draw upon insights taken from Émile
Durkheim, who gave a great deal of attention both to religion and morality. Durkheim
worked to understand the continuation of human sociality and cohesiveness even in the face
of major change, upheaval, and disagreement. He argued that public morality is an
outgrowth of social life, and saw morality as key to the sustained bonding of individuals
together into an aggregate. In his 1893 work, The Division of Labor in Society he wrote that
morality consists in a state of dependence and “its essential function . . . is to be the
integrating element in a whole, and in consequence it removes from the individual some of
his freedom of movement” (331). There is a fair amount of ethnographic evidence that the
practice of organ and tissue transfer in the U.S. offers examples of public morality at work,
in the Durkheimean sense, even as it exists as a contested domain and within a context of
ongoing change.

[5] While I do not wish to reify the effects of media or public imagery, this ethnographic
picture of faith and transplantation, and the role of public social morality, would be missing
crucial pieces if it left media representations out of the sketch altogether. One need not look
far to find that transplantation occupies a prominent seat in popular public discourse in the
U.S., largely owing to how deeply this cluster of relatively new and quickly-evolving set of
biomedical techniques and technologies engages with broadly shared social moral values (for
example, about death, the value of life and staying alive, giving, deservedness, and caring).
Such values are often reflected in human interest stories in the local news about lives being
saved by transplantation, or in worst-case scenarios portrayed in films such as the drama,
“Dirty Pretty Things” (Frears), in which vulnerable undocumented immigrants give up their
kidneys in exchange for passports, or a recent futuristic science fiction film “Repo Men”
(Sapochnik), in which persons who cannot make the payments on their artificial organs are
subject to repossession of the commodity, life-sustaining though it may be.

[6] Notwithstanding the dilemmas and debates mentioned in the opening paragraphs, and a
comparatively greater reluctance among some demographic groups to donate cadaveric
organs (Boulware et al.; Mocan and Tekin) on the whole, there is a substantial level of public
acceptance of organ and tissue transplantation in the U.S. This is especially apparent when
viewed in comparison to nation-states like Japan (Lock 2002), China, Taiwan, and Singapore
(Ikels) and Egypt (Hamdy), where this set of technologies is viewed with a great deal
skepticism. Such acceptance in the U.S. is reflected in, and likely also an outgrowth of,
publicity campaigns in support of transplantation. And in turn these campaigns, like the
public imagery and media stories described above, serve as outward, tangible illustrations of
public morality as described by Durkheim.

[7] Groups that promote organ and tissue donation and awareness (e.g., “Donate Life,”
which is a major coalition of public and private transplant community groups, foundations,
and organizations) engage with social moral values as they strategically employ various tropes and images in their publicity and marketing efforts. Lawrence Cohen, who has written about the poor in India who sell their kidneys in an effort to escape crushing debt, might count Donate Life campaigns among efforts to produce an “ethical publicity” (145, 147) for transplantation in the U.S. This concept also is taken up by Bob Simpson, who described transplant organizations’ efforts to draw upon broadly shared core values in order to motivate body tissue donation in a Sri Lankan Buddhist context. In the mainstream U.S. (generally the target audience of Donate Life campaigns), even as they are secularized, messages often tie in closely with Judeo-Christian themes such as donating “freely,” rather than out of hope for financial returns (see Sharp 1995: 364). To wit, there overall is a strong emphasis on conceptualizing donated organs as “Gifts of Life.” This trope has been critiqued by Margaret Lock, who argued, “gifts [of life] certainly have the blessing of those in authority, and they very often ‘save’ individual lives, but because organs are objectified as spare body parts and are donated anonymously, both their emotional and social worth are dissipated” (2002: 194).

[8] In addition, public moralities surrounding the value of life itself take shape in imagery that plays on meanings ascribed to the color green. Donate Life makes extensive use of green ribbons and green bracelets, and transplant imagery often draws upon notions of planting, gardening, and life taking root in new soil. Leslie Sharp (2001) has critiqued such uses of ecological themes, the color green, and motifs of recycling, gardening, and growing plants. She argues that these images obscure the origins of organs which come from the bodies of individuals who very often have died violent deaths and who inhabit the liminal space of brain death and artificial life support. In Sharp’s words, “Through green imagery, organs assume an enigmatic character, becoming mystical, fetishized objects whose use transcends their original purpose and most certainly obscures their origins” (2001: 122).

[9] Judeo-Christian references also were advanced for moral approbation, for example, in the 2010 National Donor Sabbath campaign, which featured handouts that read, “Choose life, so that you and your descendants may live. Deuteronomy 30:19,” and “May our faith fill us with the compassion to donate life” (Donate Life Nebraska). These campaigns respond to findings (e.g., Boulware et al.) that one of the major reasons why people choose not to become organ or blood donors stems from incorrect assumptions that donation is prohibited or frowned upon in their religious faith traditions, when in fact none of the major world religions explicitly forbids organ donation. Some states’ Donate Life organizations provide literature on their websites meant to educate the religious public about the perspectives of their own particular faith traditions regarding transplantation. For example, the New York Organ Donor Network website has an extensive section on religion and organ donation, providing downloadable pamphlets with titles like “Donation from a Catholic Perspective” (New York Organ Donor Network).

[10] In the U.S. Midwest, where I conducted my fieldwork, it is not uncommon to find representations of transplantation in public spaces that refer directly to religious tenets. Messages often appear on bumper stickers, t-shirts, tote bags, and billboards that read, for example, “Please Don’t Take Your Organs to Heaven – Heaven Knows We Need Them Here.” These confluences with religious faith traditions can resonate effectively with commonly shared values and notions of transplantation as a potentially important
component of one's relationship with God, one's journey in faith, and one's compassion for others. And in fact, the persons I met and spoke with in this study who most emphatically spoke of their religion or spirituality in the context of their transplant experiences, placed notable emphasis on their participation in transplantation as being facilitated at least in part by God, by “a higher power,” and/or by their faith.

Study Background

[11] This article draws primarily from a small subset of data collected during a larger ethnographic fieldwork-based research study, from 2007 to 2010. The study overall was designed to develop insights about transplantation and the kinship relationships between transplant candidates and recipients, and those who support and care for them through the transplant process. Throughout my research and writing, I’ve been most interested in understanding how the transplant process can affect kin relationships, and have come also to be taken by questions about how kinship relationships and ideologies can in turn help to shape the transplant process. I actually did not initially look closely at matters of religion in transplantation, and only asked one question in my semi-structured interviews with participants on this subject: “Do religion or spirituality play a role in your life?” with a follow up prompt (“How so?”). So in general, it was not often that my conversations with participants fully pivoted around matters of religion, spirituality, or faith. Still, it also was very rare to find someone who said that religion and spirituality played no role in their life. I then returned to the data to ask “why?” and “how?” this may be.

[12] Among those who said that religion or spirituality did indeed play a role in their life, there was a fair amount of diversity in responses as I invited them to say more. Some participants talked about not actually belonging to a church, but said that they believed in God or considered themselves a spiritual person. Others identified their denomination, or noted that they attend this or that church in particular, and some described how members of their church community had been supportive throughout the transplant process. For instance, one African American married couple said their minister had visited them several times to offer support and counsel as they prepared for the husband’s kidney transplant. Another woman of Mexican American descent in need of a kidney and pancreas transplant said that her mother was a pastor and that she had felt a great deal of support from her mother’s congregation. Several participants mentioned that members of their church community brought food to the house or helped with childcare during particularly difficult times or during hospitalizations.

[13] But a small number of patients and caregivers (a total of 12), described at length the role of religion and/or spirituality in their transplant endeavors. As they took in the magnitude of the uncertainties with which they were dealing, and carefully considered their position at the very borderlands between life and death, some seemed to infuse the entire conversation with a sense of faith-filled wonderment about their experiences. The subset of 12 participants who provided the bulk of data for this analysis placed their dealings with illness and transplant quite squarely in the realm of the sacred. (Since these participants all held Judeo-Christian beliefs, for the purposes of this paper, matters of “the sacred” will have to do with a connection to the workings of a higher power (God), and participants’ sense that their experiences emerge from an engagement with something beyond the secular, this-worldly...
aspects of transplantation.) It is important to note that, had the larger research project focused more squarely on matters of faith and religion in transplantation, interviews more consistently would have centered around these topics and there undoubtedly would have been a larger number of participants who tied their experiences to them. But the fact that religious faith and spirituality did at times comprise participants’ underlying narratives, even in the absence of such a direction in interview protocols, warrants a closer look at these matters in transplantation.

Research Design

[14] For the larger research study, I collected data during a total of 24 non-consecutive months of qualitative ethnographic fieldwork from 2007 to 2010. Qualitative methodologies like ethnography are increasingly used in health services research (Skirton: 313), and one of the ethnographic method’s greatest strengths is that it affords a context-rich representation that closely approaches the perspectives of members of the study population because the researcher directly interacts with people in everyday settings and scenarios (Tedlock). Another strength of qualitative research is that it can still yield valid and reliable data for highly relevant and sensitive socio-cultural analysis, even when the responses of study participants reveal entirely new and different themes from those originally operationalized.

[15] Ethnographic data were collected via semi-structured and open-ended interviews (the vast majority of them conducted face-to-face, with the exception of the occasional telephone interview if a participant preferred, and tape-recorded with participants’ permission), as well as informal conversations, participant observation, and the regular recording of ethnographic field notes. On an ongoing basis, data were loaded onto the software program QSR NVivo 8, which was suitable for storing, managing, coding, and indexing the multiple forms of qualitative data I collected, including textual, visual/graphic, and audio data. This software allowed searching, grouping, and analyzing the data for key general themes, patterns, and comparisons that addressed my original research questions, hypotheses, and objectives, as well as unanticipated questions and topics that emerged later, such as those addressed in this article.

[16] The central “hub” of my fieldwork was a major Transplant Center in the U.S. Midwest. Located in a metropolitan area with a population of over 800,000, the Transplant Center’s service area included both urban and rural locales, and the surrounding region’s overall population density was rather low. With written, informed consent, I met, talked with, and spent time with a total of 100 patients, caregivers, and other loved ones (a small number of whom also were living organ donors), and clinical professionals. I interacted with people in outpatient transplant and dialysis clinics, inpatient hospital rooms, and patient education and conference rooms. Two annual walk-a-thon events held for organ and tissue donor awareness, and two Annual Organ Transplant Reunions, all organized and sponsored by the Transplant Center, also served as important settings for participant observation. Several of the persons I met in these various settings warmly welcomed me into their homes and into their daily lives, and I frequently traveled to visit participants who lived within two hours of the Transplant Center. It became an invaluable part of fieldwork to view transplantation from the more deeply personal perspectives of home and family life, and I am certain that
some of the study’s overall most important insights could not have materialized without these encounters.

[17] I did not limit my sample to any one particular type of transplant, but did speak most often with those involved in kidney transplant, followed by liver, blood-forming stem cell (or bone marrow), pancreas, and small bowel transplant. Some types of transplant are often done in conjunction with others; for example, pancreas transplants often are performed along with kidney transplants. Each type of transplant is different from the next in relevant ways; for example, kidney transplantation generally is less medically complicated and has a higher success rate than small bowel transplant, which is a newer and less common procedure that carries with it greater risks and propensity for complications. Blood-forming stem cell transplantation differs in important ways from solid organ transplant. It often is used as a part of certain cancer treatments. It also need not entail person-to-person movement of tissue because it instead can involve autologous (as opposed to allogeneic) transplantation. Nonetheless, I felt there were enough similarities across the different types of transplant to be illustrative and to warrant analysis in aggregate for my dissertation. For instance, each of these types involves the use of high-tech intensive biomedical procedures, followed relatively soon after by outpatient recovery (usually in the private home); and each (with the exception of autologous marrow cell transplants) relies on the widespread and indefinite use of immunosuppressant therapies post-transplant. There also was enough consistency in the actual interview responses of patients undergoing different types of transplants to justify aggregate analysis.

[18] Due to the small number of participants upon which my analyses are drawn for this article, and to the fact that all 12 were followers of the Christian tradition, my findings are notably limited in their power to be broadly representative. At the same time, the goal of this qualitative ethnographic research project never was to be representative in a statistical sense, and the data I report and analyze here nevertheless lead to relevant insights, upon which further research can and ought to build. These insights also suggest that a re-examination may be in order regarding at least one theoretical concept from previous social science scholarship on transplantation, as I will describe near the end of this article.

Three Ethnographic Sketches

[19] In the remaining sections of this article, I will use ethnographic sketches (composed of a combination of data from interviews and from participant observation) to recount the stories of three participants in particular – two of them blood-forming stem cell transplant recipients and one of them a living kidney donor – who very strongly emphasized their religious faith throughout my encounters with them. The intent is to illustrate, as clearly as possible and with ethnographic detail, ways in which persons can experience and express their faith in and through transplantation. But beyond the experiences of individuals, who clearly gain personal strength and hope through experiencing transplantation as part of a

1 Autologous transplantation involves the harvesting of a patient’s own stem cells, which are then reserved and transplanted back into the same person following intensive chemotherapy in order to regenerate the patient’s blood and immune system after having been obliterated by the cancer treatment. By contrast, allogeneic transplantation involves the use of a donor’s blood-forming stem cells.
sacred endeavor, these sketches also point to some of the ways in which matters of faith in transplant interconnect with matters of family and kinship and the broader social moral obligations of everyday life (i.e., forms of Durkheimian “public morality”) that are wrapped up in these bonds. Faith in and through the transplant process can alternately underscore, contextualize, and reframe these ties with others. In the first example below, transplantation offered Gail\textsuperscript{2} not only the hope of being healed, but of carrying forth into a new life the hard lessons learned as she has come face-to-face with her own mortality. She describes how her priorities have been reordered, now centering on her relationship with God \textit{and} with family and friends, distilled from all the distractions of the “stuff” she once had mistakenly found so important. As we shall see, Gail’s simultaneous return to God (and a closer engagement with religious faith) \textit{and} her return to her interpersonal network of loved ones (and a closer engagement with public moral codes surrounding kinship and relatedness) are intertwined through her dealings with illness and transplantation.

Reorienting to Faith and Family: “It’s been an incredible wakeup call . . .”

\textsuperscript{[20]} On a Friday afternoon in March, I sat down with Gail and her adult daughter in one of the small conference rooms set aside in the Transplant Center for patient education sessions, instructional video viewings, family meetings, and other interactions that did not need to take place in a clinical evaluation room. At 52 years old, Gail told me she had worked her whole life, but had needed, recently and suddenly, to quit her job at the local casino which she had enjoyed very much. For a month, she had felt exhausted, and had been noticing a great deal of bruising on her skin. Suspecting that perhaps her thyroid medication needed to be adjusted, she made an appointment with her primary doctor. Her doctor performed some tests which revealed, the very next day, that Gail was gravely ill with cancer of the bone marrow, and would almost certainly die without prompt intensive chemotherapy, followed by a bone marrow stem cell transplant (or, to be more precise, a blood-forming stem cell transplant, since new technologies now allow marrow cells to be extracted from the blood rather than directly from the bones). Because her particular type of cancer severely impaired her immune system, she immediately would have to limit her exposure to even the most common germs. Her immunodeficiencies would continue through her chemotherapy treatment – which would “kill,” along with the cancer cells, any remaining immune defenses she might have had – and on through the early stages of her stem cell transplant until the transplanted cells were well established and had begun to regenerate. In addition to quitting a job in which she worked closely with a variety of people, all of whom were potential sources of contagions, Gail also would need to foster out her dogs and cats, get rid of her house plants, and cut out all fresh foods from her diet (processed foods, by their very nature, are less likely to harbor pathogens). And though she had a long-time partner who was very loving and supportive, she lived by herself on an acreage outside of a small town, and Gail’s illness, coupled with her need to limit social contacts, translated quickly into a feeling of great isolation.

\textsuperscript{2} Participants all have been given pseudonyms, and certain personal details have been obscured or changed, in order to protect and maintain their anonymity and confidentiality.
[21] Added to these changes was the fact that, even with treatment, she very likely could die from this disease, or even from the treatment itself. This fact, and Gail’s full comprehension of it, was embodied in her quivering voice and a heavy purposefulness in her emphasis and choice in words. She described to me her hope that everything would work out alright, and her trust in the doctors and other professionals at the Transplant Center. But her hands, too, materialized her apprehension as they alternately used, crumpled, and re-used tissues to wipe away tears. She spoke about priorities in life, her newly discovered and profound sense of the meaninglessness of “stuff,” (she told me emphatically, “Stuff means nothing. Nothing at all”), and her complete reorientation to family and to her personal relationships, stripped now of so many of the objects and possessions that she once had thought were so important. She already had raised the topic of faith in God earlier in our conversation, and when I asked her whether religion or spirituality play a role in her life, she answered,

Absolutely. Absolutely. I was very involved with the church when I was younger, and then as your life gets busier and life just takes on so much. And then you gotta work, you gotta raise a child, and you gotta have a car, you gotta have that house, gotta have that new TV. You get away from that. This has brought me back a lot closer with God. It’s been an incredible wakeup call. Hopefully, if I am healed, my life will be back at the church, and putting God back as one of the priorities in my life.

[22] Gail’s illness not only terrified her, but also demanded a revision of her relationship to material possessions. She once felt beholden to a hectic lifestyle that enabled and sustained such purchases as a car, a house, a new TV, etc. But while it was difficult to give up some of her everyday material comforts, she also now considers them to have been an obstacle to her more important connections both to family and to God. Now facing the very real possibility of death, along with having been made to do without certain valued possessions, as Gail encounters illness, treatment, and transplantation, she has re-ordered her priorities and rediscovered both family and faith through it all.

[23] While Gail felt she was being brought back into a faithful relationship with God through her experiences with illness and transplant, the other two examples I will detail below involve persons who did not report having previously strayed from their faith. Rather, persons in the next two cases found evidence that God was speaking to them directly concerning transplantation, and they were beholden to take part in the transplant process as a way of keeping within a divine plan. At the same time, as will become apparent, their relations to family and kin were so deeply implicated as to be inseparable from their ongoing conversations with God.

Honoring Obligations: “I finally trusted in the Lord . . .”

[24] Upon learning that she would need to have a port placed in her skull to deliver chemotherapy directly to a brain tumor, and that she would need to have a bone marrow stem cell transplant as part of her cancer treatment, Annette, a 57-year-old devout Catholic, turned to her husband and said “call our son home from Iraq; I just can’t go through with this.” With the transplant, Annette had been told, her odds of surviving increased from between ten and twenty percent to about fifty percent. Just four years earlier, she had been diagnosed with – and had survived – breast cancer. Differing from Gail in the first example,
Annette did not fear death. Her faith had long been on solid ground, permeating her everyday life; she felt confident that her relationship with God was in proper order and that she could look forward to a heavenly afterlife that would be free from the pain and suffering she knew would come with the prescribed cancer treatment. But as she and I talked the first time we met, by then well into her post-transplant days, Annette recalled how her friend, her husband, and her sisters all had worked to convince her that she needed to attempt the chemotherapy and transplant, because she was needed here, in this life.

Throughout this and our subsequent conversations together, Annette infused her descriptions of her experiences with references to “salvation,” “prayer,” and a “Suffering Savior.” For example, as she described her process of moving forward with the treatment, she said, “the neurosurgeon took an hour and a half to explain everything to me – he was like another piece of salvation that just dropped in my lap.” During her time as an inpatient and in her post-treatment recovery, Annette had a network of family members and close friends who called themselves “Annette’s Prayer Team.” She even had been given a sweatshirt screen printed with the signatures of her Prayer Team members, all of whom were actively praying for her and for her doctors and nurses. And as she explained how she eventually came to see the value in going through the tremendously uncomfortable treatment and transplant process, she referred to the coaxing and encouragement of the closest members of her kin and social network, who argued that she needed to go on living in order to “be there” for her children and grandchildren. She noted, “If we didn’t have a Suffering Savior, I wouldn’t believe a word of it.” Here, Annette likely is referring to the tenet of Christianity which holds that Jesus Christ willingly accepted suffering (i.e., though he had committed no crime, he was tortured and died by crucifixion) for the salvation of all of humanity. This fostered her realization that she, too, would need to accept suffering for the sake of her family. Importantly, along with being convinced that her family needed her to go on living, and that the treatment and transplant were her only chance of doing this, Annette said, “I finally trusted in the Lord and said, ‘Lord, alright I’ll do this and I’m gonna offer it up for your kingdom. And so whatever good you can bring out of it, I’ll put my best foot forward.”

Annette compared her own situation to that of her sister and her brother who each had died of cancer, as well as another sister who has multiple sclerosis, and a friend who has ALS (or, Lou Gehrig’s Disease), all of whom would have loved to have a treatment available that could offer them some hope, as the transplant did for her.

Those are part of the conversations I have with God. But to be able to live here today in [this community] with the world’s leading people, how could I not do the transplant? I thought, I am not in some third-world country starving to death, dying of who-knows-what. I thought, I am a blessed woman. I’m in a position and I have insurance, and how could I not? That’s really what I finally decided, was how could I not use this opportunity? How could I turn around and go crawl in bed and say, “No, let me die”? No I couldn’t do it! Out of the billions of people in the world, how many have the opportunity that I have had? [ . . . ] There were days I woke up and said ‘Lord, you weren’t listening when I said I didn’t want to do this anymore.’ And now I wake up and am so grateful that I have another day.
Annette points out that she's extremely fortunate to live in close proximity to a major stem cell transplant center, and likens the prospect of deciding not to do the transplant to turning away blessings from God, which in her view not only would be an imprudent, but an immoral act. Annette’s participation in the treatment and transplant was simultaneously both a fulfillment of her obligations to her kin and a way of faithfully honoring her relationship with God.

[27] Annette’s faith had long permeated her life, and continuously infused her daily interactions with purpose and significance. She described her regular practice of writing down on whatever piece of paper is handy at the time, anything she comes across that is meaningful or inspiring to her. During Advent one year, when her own children were still young and long before her first cancer diagnosis, Annette had come across a passage from the Bible, Psalm 91:14-16, in which God promises to answer those who call, to be with them in times of distress. Many years after she had written down the Psalm, Annette had been tutoring a little boy who had autism and impaired communication skills. She had to give this up, however, when she first learned she had cancer. The boy’s new full time tutor periodically brought him over to Annette’s house for short visits, just to stay in touch. They stopped by once while she was waiting to begin her chemotherapy treatment. And during this visit he walked into Annette’s bedroom, and then walked out and handed to her the very piece of paper on which she had written the Psalm so many years ago. While she was telling me this, Annette paused, got up, and went across the room to show it to me. “I always keep it with me...” she said. And when this boy handed it to me, I had no idea where he found it in my room. And I hadn’t seen this paper in years! And he never spoke in sentences and never unprompted. And I had just told the Lord, I said, “Alright, I’ll do it (meaning the treatment) but you gotta give me something to hold onto.” Isn’t that amazing?!

Annette held this experience as not merely a coincidence, but rather an occurrence belonging in the category of the sacred. She also took it as God speaking to her through a very human connection, a human act. Though this incident took place the first time Annette had cancer, she points to it as something she has carried with her, noting that it played an important role in helping her through her second diagnosis, chemotherapy, and stem cell transplant as well. It suggests, again, the melding of matters of faith and a relationship with God with matters of human social connection in and through the transplant process.

[28] The first two examples have involved blood-forming stem cell transplantation and highlighted the experiences of persons for whom transplantation was crucial to any hope of surviving a grave illness. But the third example, below, involves a living kidney donor – Jerald – for whom transplantation technically created risks to his health that otherwise would not have existed. But not altogether different than Annette, Jerald felt that God had called him directly to participate in transplantation. As we shall see, he felt very strongly that his donation to a brother-in-law was a sacred connection of the highest sort, very literally facilitated through a summons by “a higher power” to come forward with his offer of a kidney.
Sacred Relations: “I gotta say . . . it’s a higher power”

[29] Jerald and his wife, Alice, sat together one afternoon as they read an email from Alice’s sister, addressed to the extended family. In it, they learned that Alice’s sister’s husband had experienced a decline in kidney function so significant that he would need to pursue a kidney transplant. Almost immediately, a powerful sense came over Jerald. A 60 year old auto mechanic with his own business, who had been born and raised in the rural northern Midwest, Jerald had led a relatively quiet life. He had long resided in a small community, raising three children and now enjoying grandchildren, with his wife of 34 years. They both are Lutherans for whom faith is woven into the very fabric of their (and many of their neighbor’s) daily lives. The family had known for years that Alice’s brother-in-law had polycystic kidney disease, and that he someday would need a transplant. But this knowledge about the inevitability of kidney failure did not assuage the anxiety and grief over actually coming to that point in the disease process, and as Jerald described it, the worry was palpable in the email.

[30] Alice’s sister also had mentioned her husband’s blood type in the email, explaining that people with this blood type tend to have a long wait for a kidney. Jerald immediately noted the blood type “in black letters,” telling me, “I looked at Alice and said you know? That’s what I am.” And even before all the blood work had been completed to confirm that the two men were indeed a very close match, Jerald said he somehow knew that he was going to be the donor. Alice described her initial reaction when Jerald said he thought he could be the donor: “I gulped . . . but he said it with such determination,” and she now fully supports his decision. Jerald explained his immediate sense about the donation as one might explain a religious calling.

   I gotta say, Laura, it’s a higher power. I really do, because I was sitting at the table and it was just like somebody tapped me on the head. I’m not kiddin’ ya. Just like somebody tapped me on the head, “Jerald, do that!” and I just . . . did.

In separate interviews with Jerald and Alice, each one indicated that they’ve felt like this donation is something that simply is “supposed to be.”

[31] Throughout our conversation together, Jerald emphasized his certainty about becoming a donor. Importantly, he connected his absence of doubt both to the clarity with which he perceived a prompting from God, and to his membership in a kin network in which he would do the same for anyone else:

   I’m just very comfortable about the whole deal. I haven’t lost one minute’s sleep about this. I’m not gonna look back and wish that I hadn’t done it because I know that if I can improve the quality of his life, it’s well worth that. And I would do it for any one of my brothers or brother-in-laws . . . it’s

---

3 Polycystic kidney disease (PKD) is an inherited genetic condition, which can cause numerous large cysts to grow in the kidneys, enlarging them, changing their structure, and often limiting or altogether ceasing their ability to function and filter wastes from the body (NKUDIC 2011). Many of the persons I met in this study needed a kidney transplant because they were in renal failure brought on by PKD.
just something I wanted to do. [. . .] From the very beginning, with the email from the very beginning, it was just clear in my head, this is what I’m gonna do. And I just haven’t wavered or given a second thought or a negative thought since. So I’ve just gotta say somebody planted that seed in my head. You just don’t do that for the heck of it.

Still, while both Jerald and Alice had complete faith that Jerald was meant to become a living donor, they both reported trying to protect Alice’s sister and brother-in-law, the potential recipient, through the process. For example, as Jerald now has to undergo various medical and psychosocial tests and procedures in order to ensure that he is physically and emotionally prepared for the donation, Alice voices her concerns to one of her other sisters, and does not mention them to the sister whose husband needs a transplant. As another example, Jerald said he has been surprised at how tremendously supportive others have been, and has noticed a tendency for people to hold him up as a hero. But Alice added that they would rather not have this type of attention from others, in part out of their own affinity for privacy, but also out of an effort to shield their brother-in-law from any potential social scrutiny that could come with being a recipient of a living organ donation. Though he currently lives several hours away, he still has ties with Jerald and Alice’s small community through family and friends, and the couple would prefer that the matter not be the topic of local gossip. And from the beginning of this journey, Jerald did not talk to his brother-in-law about coming forward as a donor until there was clinical certainty that the two were physiologically considered a good match for transplant. When he did in fact make the phone call to share the news, Jerald framed the decision as his own, and one that was not up for debate:

He just didn’t know what to say. He almost told me “forget about it” because he says, “Jerald, you’re a Grandpa, you can’t do that for me.” I said, “I most certainly can. I just made up my own mind, this is what I was gonna do.” And I knew from the instant that I saw his blood type, I said I’m going to do this. Come hell or high water, I’m going to do this, and that’s what I’ve been doing.

This suggests that, while Jerald himself felt his donation was part of a larger plan, he also positioned himself firmly within his social moral obligations to give out of his own free will, and to actively shield his brother-in-law from any sense of guilt about the donation.

While his brother-in-law ultimately did accept Jerald’s offer, as Alice puts it, both men are “quiet Norwegians” who do not always freely verbalize their deepest thoughts and feelings. But during a trip the donor couple was making to the Transplant Center as part of Jerald’s evaluation and preparation, Jerald and Alice stayed at the home of her sister and brother-in-law. Alice noted that being together at her sister’s and brother-in-law’s home and talking, the four of them together, turned out to be a crucial part of the process. The recipient couple had a chance to express to Jerald and Alice their own concerns about

[32] Still, while both Jerald and Alice had complete faith that Jerald was meant to become a living donor, they both reported trying to protect Alice’s sister and brother-in-law, the potential recipient, through the process. For example, as Jerald now has to undergo various medical and psychosocial tests and procedures in order to ensure that he is physically and emotionally prepared for the donation, Alice voices her concerns to one of her other sisters, and does not mention them to the sister whose husband needs a transplant. As another example, Jerald said he has been surprised at how tremendously supportive others have been, and has noticed a tendency for people to hold him up as a hero. But Alice added that they would rather not have this type of attention from others, in part out of their own affinity for privacy, but also out of an effort to shield their brother-in-law from any potential social scrutiny that could come with being a recipient of a living organ donation. Though he currently lives several hours away, he still has ties with Jerald and Alice’s small community through family and friends, and the couple would prefer that the matter not be the topic of local gossip. And from the beginning of this journey, Jerald did not talk to his brother-in-law about coming forward as a donor until there was clinical certainty that the two were physiologically considered a good match for transplant. When he did in fact make the phone call to share the news, Jerald framed the decision as his own, and one that was not up for debate:

He just didn’t know what to say. He almost told me “forget about it” because he says, “Jerald, you’re a Grandpa, you can’t do that for me.” I said, “I most certainly can. I just made up my own mind, this is what I was gonna do.” And I knew from the instant that I saw his blood type, I said I’m going to do this. Come hell or high water, I’m going to do this, and that’s what I’ve been doing.

This suggests that, while Jerald himself felt his donation was part of a larger plan, he also positioned himself firmly within his social moral obligations to give out of his own free will, and to actively shield his brother-in-law from any sense of guilt about the donation.

[33] While his brother-in-law ultimately did accept Jerald’s offer, as Alice puts it, both men are “quiet Norwegians” who do not always freely verbalize their deepest thoughts and feelings. But during a trip the donor couple was making to the Transplant Center as part of Jerald’s evaluation and preparation, Jerald and Alice stayed at the home of her sister and brother-in-law. Alice noted that being together at her sister’s and brother-in-law’s home and talking, the four of them together, turned out to be a crucial part of the process. The recipient couple had a chance to express to Jerald and Alice their own concerns about

—

4 The use of the terms “donor couple” and “recipient couple” here is purposeful, and meant to indicate how participation in transplantation is not an individual matter, but rather impacts larger kinship and social networks.
Jerald’s health, and to ask questions about how the donor couple was going to manage finances while Jerald was still recovering and unable to work. They were able to ask Jerald again whether he was sure about this, since he is in fact a grandfather, and wanted to know what the couple’s three adult children truly thought about it all. As Alice explained, it was so important to physically be present together with each other in order to fully communicate about the matter. Now having the complete spectrum of body language and voice inflection available to them, the laughter, tears, and emotion of it all “just poured out,” and allowed each of them to move forward in the transplant process without hesitation. Jerald noted that he and his brother-in-law had had a good relationship prior to this, but that moving through this journey together has brought them even closer to one another.

[34] In Jerald’s experience, the “somebody” who “planted the seed” in his head to become his brother-in-law’s living kidney donor was none other than God; his participation in transplantation was quite literally part of a sacred endeavor, prompted by a higher power. Yet, returning to an earlier quote, Jerald said he would have performed the same act for any one of his brothers or brothers-in-law (or any other family for that matter). This lends further support to the notion that the human kinship connections that inhere in transplantation do not go by the wayside, but rather come to the fore even as persons engage in the process as an outgrowth of faith.

Implications and Conclusions

[35] Faith clearly can support, strengthen, and anchor a person through the uncertainties and upheavals of the transplant process. At the same time, each case I’ve presented here also offers an example of someone practicing their religious faith through participating in transplantation. In doing so, these participants lifted the relevance of their dealings with the medical tests, treatments, and procedures of transplantation into a more sacred sphere. Importantly, though, their experiences with faith were not purely personal or individualistic. Drawing upon another sense of the term, each participant also had a certain level of “faith,” or trust, in transplantation as a means toward remaining alive [or enabling another to go on living] and continuing to serve as valued members of kin and social networks.

[36] Thus, as they engaged in matters of faith in and through transplantation, Gail, Jerald, and Annette also were following codes of public morality, which call for persons to carry out their social moral obligations to others in their lives, particularly members of their kin networks. Gail did so through a reprioritization of relationships with family and friends, toward the exclusion of meaningless “stuff” (like televisions, houses, and cars) that also once had led to her disengagement with God. Annette did so by agreeing to attempt, through treatment and transplant, to remain alive not only because she did not want to eschew God’s blessings, but also because her family needed her, even though she herself initially was reluctant to undergo the treatment. And although Jerald doesn’t deny his own role in his becoming a living kidney donor, his faith that God was a major player prompted Jerald to give his kidney freely, willingly, and without hesitation. This resonates closely with the religious imagery employed in campaigns to increase organ donation (which I described above) and the connections of these images with public moral values upholding the importance of giving unreservedly, without being asked directly by the actual person in need, out of a sense that it’s in answer to a larger, spiritual call to be generous. This also effectively
shields the recipient from some of the potential emotional and social discomforts with receiving such a magnanimous gift.

[37] These findings all have potential implications for future directions in social analyses of transplantation. For example, in many ways, the lifting of his act of donation to the realm of the sacred also facilitated a strengthening of Jerald's bond to his brother-in-law that was potentially free of some of the “tyrannous” aspects of the gift, about which transplant scholars such as Fox and Swazey (383) have written extensively, and may warrant a re-examination of this theoretical concept (although see Kaufman, Russ, and Shim for examples of some of the potential discomforts with kin-based living donation). Fox and Swazey base their concept on the obligatory aspects of gift-giving outlined by Mauss, but focus most heavily on the obligation to reciprocate gifts given, arguing that the inability to ever actually reciprocate the gift of a donated organ creates a potentially oppressive relationship in which one party is forever indebted to the other. Fox and Swazey, however, pay less attention to the other two oblations described by Mauss: to give and to receive. Thus, the notion of “the tyranny of the gift” of a donated organ does not adequately account for instances like the one described above, in which an organ is given out of deeply held convictions (Jerald being prompted by God, and himself feeling a deep sense of purpose), and received only with convincing (his brother-in-law being told by Jerald that his mind was made up and the matter was not up for debate). Such a situation, especially to the extent that it is facilitated by the will of a higher power, is one over which neither giver nor receiver enjoys complete agency, and may reduce the emphasis on direct reciprocity and mitigate some of the tyrannous aspects of the transfer.

[38] An appraisal of one’s personal relationship with the sacred also can help to (re)frame, contextualize, and draw attention to the place and role of kin relationships and other social moral connections through the journey. This builds on the notion, which I argue more fully elsewhere (Heinemann) that transplantation, as both a set of medical procedures and as a social phenomenon, reverberates throughout kin and social networks and necessarily impacts lives extending well beyond the individual patient. While I have not taken up the matter of body commodification here, and only hinted at some of the scholarly treatment of this matter by medical anthropologists such as Cohen and Sharp (in addition to 2001, cited above, see 1995, 2000, and 2006), my findings also shed light on social phenomena (the interconnections between faith, public moral codes, and social moral obligations among kin and others), which likewise comprise key components of this picture.

[39] Thus, through these analyses, I hope to add to the ongoing conversation about transplantation. One of my broader aims is to more holistically understand the phenomenon, and to round out the empirical ethnographic picture from which we draw our analyses. In sum, as a modest step toward this goal, and relying on the findings I have presented here, I would like to suggest that as some participants put their faith in the transplant enterprise, their involvement represents an engagement in two endeavors: 1) a sacred religious endeavor in which they practice their faith in the transplant process, and 2) a public endeavor in which they practice their social relatedness and kinship obligations to others. Rather than being separated, though, these two endeavors are interrelated and interdependent, and both together engage with common mainstream ideologies and public moralities, materialized also
in the imagery and discourses described near the beginning of this article, which resonate with and sustain the ever-evolving practice of transplantation.

Acknowledgement

I would like to express my most sincere and humble gratitude to each of the patients, caregivers, and clinical professionals who so graciously and generously agreed to share their insights and expertise with me throughout my fieldwork. While I have stayed as close as possible to the information I was given along the way, any potential errors or misrepresentations that may appear in this text are solely the product of my own oversight.

The research on which this article is based also would not have been possible without the generous support of several funding organizations and programs, including: The National Science Foundation (BCS – Cultural Anthropology) Doctoral Dissertation Improvement Grant; University of Michigan Center for the Education of Women Cecilia Anne Stiborik Dreyfuss Scholarship; University of Michigan Rackham Graduate Student Research Grant; University of Michigan Social Work-Social Science Summer Funding; Creighton University Department of Sociology and Anthropology Visiting Scholar Program; University of Michigan Susan Lipschutz Award; University of Michigan School of Social Work Alumni Award; University of Michigan School of Social Work Doctoral Dissertation/Thesis Grant; University of Michigan School of Social Work Henry J. Meyer Scholarship Award; University of Michigan Rackham/Department of Anthropology Block Grant; and University of Michigan Rackham One-Term Dissertation Fellowship. To each of these organizations and programs, I am deeply grateful.

Bibliography

Boulware, L. Ebony, Lloyd E. Ratner, Lisa A. Cooper, Julie Ann Sosa, Thomas A. LaVeist, and Neil R. Powe

Browning, Colette J., and Shane A. Thomas

Cohen, Lawrence

Donate Life Nebraska

Durkheim, Emile
Fox, Renee C., and Judith P. Swazey  

Frears, Stephen, director  

Hamdy, Sherine  

Heinemann, Laura  

Ikels, Charlotte  

Jones, Jill B., and Marcia Egan  

Kasiske, Bertram L., David Cohen, Michael R. Lucey, and John F. Neylan  

Kaufman, Sharon R., Ann J. Russ, and Janet K. Shim  

Kleinman, Arthur  

Lock, Margaret  


Marshall, Patricia A  
Mauss, Marcel

Maynard, Ronald J.

Mocan, Naci, and Erdal Tekin

National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC): A service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health

New York Organ Donor Network

Sapochnik, Miguel, director

Sharp, Lesley A.

Simpson, Bob

Skirton, H.
Tedlock, Barbara

Ubel, Peter A., and George Loewenstein